

DEPARTMENTS OF LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION, AND RELATED AGENCIES
APPROPRIATIONS FOR 1992

HEARINGS
BEFORE A
SUBCOMMITTEE OF THE
COMMITTEE ON APPROPRIATIONS
HOUSE OF REPRESENTATIVES
ONE HUNDRED SECOND CONGRESS
FIRST SESSION

SUBCOMMITTEE ON THE DEPARTMENTS OF LABOR, HEALTH AND
HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

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and JOANNE L. ORNDORFF, *Subcommittee Staff*

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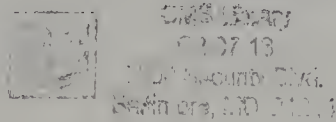
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NOTE.—The Honorable Silvio O. Conte was Ranking Minority Member of the Committee until his death on February 8, 1991.

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 1992

TUESDAY, MARCH 19, 1991.

DEPARTMENT OF HEALTH AND HUMAN SERVICES FISCAL YEAR 1992 BUDGET PROPOSAL

WITNESS

HON. LOUIS W. SULLIVAN, M.D., SECRETARY, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. NATCHER. The committee will come to order. At this time, we take up the budget request for the fiscal year 1992 for the Department of Health and Human Services. We have before the committee at this time, Dr. Louis Sullivan, the Secretary.

We are glad to have you here today. Our subcommittee believe you are doing all right.

Secretary SULLIVAN. Thank you very much.

Mr. NATCHER. If I didn't mean it. Mr. Secretary, I wouldn't tell you that, we are glad to have you. As you know, the budget that you have before the committee has an increase in it of about \$12.5 billion. Most of this increase, of course, is for entitlement programs.

I am particularly pleased that the budget carries an increase of \$498 million for the National Institutes of Health and, Mr. Secretary, that is good. When I started out on this committee, we had \$73 million for the National Institutes of Health. We are up now to about \$8.2 billion. If I had my way, it would be \$10 billion is where we should spend our money.

Unfortunately, as you know, we also have in the budget request a decrease of about \$586 million in the Energy Assistance Program—a program that our old friend, Silvio Conte, was very much concerned about always.

But, generally speaking, the budget, you have submitted to our committee, I think, is a good budget for us to start with.

You are fortunate, Mr. Secretary, when you come out with an increase from the Office of Management and Budget. The other two Departments in this bill can't say the same thing.

As I said before it is a pleasure to have you before the committee. Before you give us your statement, I am going to yield to Mr. Pursell and Mr. Early.

Mr. PURSELL. Thank you, Mr. Chairman.

It is an honor to have you here, Dr. Sullivan. We have the highest respect for you and your leadership. I had the opportunity yesterday to spend all day at the National Institutes of Health, from

8:00 in the morning until 6:00, to get a solid briefing on the great research we are doing for the Nation.

I am very impressed with not only that program, but I think, as the chairman indicates, our needs and health needs of this country are so crucial, and I appreciated your articulation of issues, such as infant mortality, non-smoking programs that help get that message out to the country, and other key programs.

I am very honored to have you before our committee today.

Mr. NATCHER. Mr. Early, I yield to you.

Mr. EARLY. Thank you, Mr. Chairman.

I want to echo basically, Dr. Sullivan, what Mr. Pursell and the chairman have said. I think the chairman said it best when he said we have known you for a long time, and we know where your basic values are.

I appreciate the statement that you made the other day, and I also recognize those types of moral things we have to do. At the same time, we have to let the government provide the impetus to get us there more quickly.

Our role is to get us there more quickly. A lot of judgments have to be made. We can't do as we have done in the past, throw a bucket of money. The problems are there, such as infant mortality. The chairman said he would put in \$10,000,000,000. I thought he used to say \$15,000,000,000.

Mr. Natcher, I think you always said you would spend 1\$5,000,000,000 in NIH, and we would get \$50,000,000,000 worth.

I'm very glad to see you, Dr. Sullivan.

Mr. NATCHER. Dr. Sullivan, we will be pleased to hear from you.

SECRETARY'S OPENING STATEMENT

Secretary SULLIVAN. Thank you very much, Mr. Chairman, and members of the committee.

It is certainly a pleasure and honor for me to have this opportunity to appear before you to present my Department's budget.

Over the years, prior to coming into this position, I certainly, as you recall, appeared before this committee and always was extended many courtesies. And certainly, since I have been Secretary, it has been indeed a very good working relationship that we have enjoyed with this committee. And for that, I am very grateful.

You mentioned Mr. Conte, Mr. Chairman. We certainly had a very good working relationship with Mr. Conte, and he, as you know, was very committed to the National Institutes of Health and the programs there. And certainly, we will miss his input here on this committee.

I am certainly pleased Mr. Pursell is the ranking Republican on the committee, because I have known him. Shortly after I was sworn in, he had me out in Michigan meeting some nursing home directors who were demanding explanations from me for some of the regulations that we had issued from my Department, so I have known from that time that he has a keen interest in the various programs of our Department.

So, I am very pleased that he is certainly providing leadership on the minority side here on the committee.

Mr. PURSELL. Thank you.

Secretary SULLIVAN. Now, as you know, I have submitted for the record a full overview of our Department's programs, but I would like to amplify some of those things in my oral presentation to you today.

Specifically, I would like to focus my comments on programs and initiatives on behalf of our Nation's children. And by doing that, to highlight this Administration's thoughts about how to best confront the many serious health and economic issues confronting our children.

Let me begin by speaking about a trip I took at the request of the President back in January, a trip to Africa that he instructed me to take at the time of the U.N. Summit for Children.

At that world summit, there were 73 Heads of State, the largest gathering of Heads of State at any meeting ever. We were looking at the issue of child health, welfare and survival around the country.

And the President indicated that he would have me and Dr. Ronald Roskens, head of USAID, visit Africa to see what more the United States and other nations should do to assist in child health and child survival on that continent, as well as to focus on the AIDS epidemic that, like here in the United States, is confronting the countries in Africa as well.

So, this past January, I led a delegation of about 17 individuals from my Department and from the U.S. Agency for International Development in visiting some eight countries in Africa.

We were warmly received in each of the countries that we visited. What was striking to us was the degree of disease and disability that we saw in those countries. Diseases which have long disappeared from the United States are still confronting them. They still have children dying from measles, from infant diarrhea, malnutrition, and childhood communicable diseases. They are confronting a growing AIDS epidemic in many of those countries that was indeed heart-rendering to all of us.

Now, one of the things that was striking to us is, in spite of this very heavy burden of disease and disability, health professionals, and community leaders were working, oftentimes with very startling results in addressing some of the health care issues on that continent.

And, as we reflected on that visit, it also was a striking contrast that here in the United States, we also are confronting problems with child health and child welfare, but here the problems are more social in origin than medical.

And it means that we must have the imagination, the creativity and the will to focus our resources in a more effective way to address issues of child health and child survival in a more effective way. Because, as you know, and I have said before this committee, the United States spends more money per capita for health care than any other nation in the world.

And yet, in some basic health indices, we lag far behind. Our infant mortality data is one of those areas where we rank 24th among the nations of the world, although we rank number one in terms of dollars that are spent. That says to me that we have to find ways to spend our dollars more wisely, to organize our services more efficiently, to have better outreach and to find—and remove

those barriers to health care that exist in our communities, so that we can be sure that all of our citizens enjoy the benefits of our high technology, our very sophisticated state of medical knowledge that is the result of the work of the National Institutes of Health over the decades.

We have had many miracles coming from the work of the National Institutes of Health, Mr. Chairman. As a medical student, I was taking care of patients with paralytic polio, whereas in 1990, there were no reports of it coming to the Department. We are beginning to talk about the possibility of being able to eradicate polio from around the world, very much as we eradicated smallpox in the early seventies.

So, we have marked contrast in our health care system, with the most advanced health care knowledge, technology, and highly-trained professionals in the world, however, we have some glaring health data caused by a number of social factors.

One that we are quite familiar with is the high rate of family breakups in the United States. One out of two marriages ends in a separation and a divorce. Many children are raised in single-parent families or in a home where both biological parents are not present. Many have felt that this environment is quite appropriate; many single-parents are doing excellent jobs raising their children under difficult circumstances.

But the research data is irrefutable about children from single-parent homes having a higher incidence of trouble with the law, dropping out of school, becoming single parents themselves, or involved with drugs.

Mr. Chairman, you will recall that last August, we released our Health Goals for the Nation for the Year 2000 at a conference here in Washington, attended by 1500 people from all over the country.

These 298 goals, are realistic, we feel they can be attained with good organization and determination by the year 2000. These goals are an explicit recognition of the fact that major advances in the health of our citizens for this decade will come about if we can improve our health behavior.

Of the top 10 causes of death in the United States in 1991, every last one of them is influenced significantly by personal behavior, whether it is cancer related to smoking or inadequate breast mammography, lack of Pap smears, heart disease resulting from lack of exercise or high fat content in the diet; problems with drug abuse, violence, high infant mortality caused by a lack of prenatal care, et cetera.

All of these are factors influenced by personal behavior, and that is why I have been as outspoken as I have about personal responsibility. We have to have a partnership with our citizens because all of the technology and sophisticated knowledge we have goes for naught if our citizens don't use it, or there are barriers to their access.

At the turn of the century, the life expectancy in the United States was around 47 years. Our life expectancy now is 76 years, which is a remarkable improvement. Diseases that were killing U.S. citizens at the turn of the century were infectious diseases: Diphtheria, tuberculosis, and vitamin deficiency diseases. Those have virtually disappeared now with the advent of better nutrition,

understanding about vitamins, development of antibiotics, and public health advances for safe water and food.

Now the diseases that are killing us are heavily influenced by personal behavior. And therefore, for us to make major advances, we have to have the partnership and the active work of our citizens, our citizens have to understand that they are part of the process; that they can no longer be passive individuals in terms of their health or our health care system.

We have among the initiatives in our budget, Mr. Chairman, one to address the high infant mortality rate in our country that has caused a lot of controversy. As you know, we are working, as you are, under the budget agreement that was agreed to by the Congress and the President last year. This means, we are now forced as never before to make choices in priorities.

And because of the fact I consider a high infant mortality rate not only shocking, but actually disgraceful, I think we have to move that up higher among the priorities.

What we have proposed for our 10 demonstration projects is find better ways to marshal our resources in a more effective way to lower infant mortality rates in our country, and then use the data from these demonstrations that will have as a goal to reduce the infant mortality rate in those areas by at least 50 percent within a five-year period. Then, to use that information for the whole country.

While there are not surprisingly a number of people who have been concerned about whether we would be diverting funds to this effort, I maintain that this is an investment for the whole Nation.

The data coming out of this will be helpful to all 550 of our community health centers, and all of our hospitals, physicians and other health professionals. Because what we are doing now, while having some impact, and certainly we have lowered our infant mortality rate since the 1970s, but the rate of fall during the last decade has been slowed, so that we need to find ways to accelerate that.

So, that is one of our—one of our proposals that we would be pleased to discuss with you.

We also are very proud of our Head Start program. We have had a 66-percent increase in the Head Start budget. This program is now about 26 years old, and provides educational, nutritional and medical benefits to the children.

Over three budget cycles, we have added a total of 633,415 children that will receive at least one year of a Head Start experience prior to entry into school. This program works, and we are pleased to have been able to expand it.

It is my feeling that part of my responsibility is to get the message to our citizens that each of them has a role to play in sharing and accepting personal responsibility for their health, their family's health, and to work within our communities and neighborhoods to make them safer and healthier environments for our children.

The report recently released from our Centers for Disease Control showed violence is the number one killer of black males in our society at ages 15 to 24, that represents many factors, such as the

breakdown of families, sense of neighborhood, and a loss of role models.

I maintain that the Department of Health and Human Services is the first family. As you look at each of the 250 programs for which we are responsible, they are programs that are designed to shore up or substitute for or reinforce the family.

Therefore, the stronger the family ties, the less the need and the demand for the services of my Department. And, obviously, the healthier the environment for our children to grow up in.

Mr. Chairman, that completes the statement that I wanted to present to you, and I would be very pleased to respond to questions from you and members of the committee.

[The statement of Secretary Sullivan follows:]

STATEMENT OF LOUIS W. SULLIVAN, M.D.

HOUSE LABOR/HHS APPROPRIATIONS SUBCOMMITTEE

MARCH 19, 1991

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MARCH 20, 1991

Mr. Chairman and Members of the Committee, thank you for inviting me here today to discuss the President's fiscal year 1992 budget proposal for the Department of Health and Human Services. Our budget totals \$525 billion, an increase of \$39 billion, or 8 percent over current year spending.

Our appropriation request for HHS programs considered by this Committee totals \$161 billion. This is \$13 billion over 1991, or an increase of 9 percent.

This budget reflects the President's and my own priorities for the programs and services delivered by this Department and I look forward to working with the Congress for the enactment of this budget.

We find ourselves at a unique time in our ability to address the health care needs of this Nation. We are faced with grave public health challenges such as unacceptably high rates of infant mortality--particularly in our minority communities, the devastating impacts of drug abuse, and far too many deaths from preventable diseases. These problems and others extract an enormous toll from our society in terms of personal suffering as well as spiralling socio-economic costs. Certainly these problems cannot be solved overnight. However, we can have a tremendous impact by using our resources to improve both the scope and delivery of our health care services, by expanding our understanding of life processes and disease through research, and

by calling on every citizen to take personal responsibility for making positive, healthy choices for their lives.

During 1992, we will continue our work to improve the health and well-being of this Nation by helping children and strengthening families; by improving the health status of minority and low-income Americans; by intensifying disease prevention and health promotion activities; by advancing our scientific understanding of the basic biomedical and behavioral research opportunities before us; and by continuing to improve the delivery of programs and services for which we are responsible.

I would now like to share with you, in greater detail, how our 1992 budget will help us to be responsive to the enormous challenges before us:

During 1992, HHS will provide over \$6 billion for child care, child development and child welfare programs for America's families in need. This amount represents an increase of \$659 million, or 11 percent over 1991 levels. Let me briefly highlight these programs for you.

The 1992 budget proposes spending \$4 billion on child care and development, a \$366 million or 11 percent increase over 1991. These programs recognize the critical role that child care plays in assisting low-income families achieve and maintain economic

self-sufficiency. Included is \$732 million for the new Child Care and Development Block Grant enacted by Congress last Fall; \$300 million for At-Risk Child Care grants which will provide child care to families at risk of becoming dependent on welfare if it were not for child care assistance; \$350 million for child care that will support Aid to Families with Dependent Children (AFDC) recipients' efforts to leave welfare; and \$83 million for Transitional Child Care to help prevent families from returning to welfare.

As you know, educating our youth is a top priority of this Administration. The Head Start program has been one of the most important and successful governmental efforts to help children enter school ready to learn. This budget includes \$2 billion for Head Start, an increase of \$100 million over 1991; the amount of our increase was dictated by our management concerns for the program. These funds will be used not only to expand enrollment in the Head Start program but also, most importantly, to assure the proper management of the huge infusion of funds Head Start has received over the past two years. We are very pleased to report that by the end of FY 1992, the Head Start program will enroll 180,000 more children than we did before President Bush and I came into office.

State Child Welfare Services agencies and Foster Care and Adoption Assistance programs cope with large numbers of troubled

children and families and create homes for many of our Nation's children. The 1992 budget includes \$2 billion for payments to States for Foster Care and Adoption Assistance, \$203 million above the 1991 level, for children currently in foster and adoptive homes. The 1992 budget also provides \$364 million for Child Welfare Services, a \$90 million or 33 percent increase over 1991, to strengthen efforts to prevent children from entering foster care.

The Department will also enhance efforts to protect children from abuse and neglect. Funds are requested to increase coordination of child abuse and neglect prevention efforts, evaluate treatment innovations, and implement a new National Child Abuse and Neglect Reporting System to further our understanding of the causes and extent of child abuse and neglect.

As Secretary of HHS, one of my top priorities is to lessen the burden of disease, disability and premature death which disproportionately affects many of our poor and minority citizens. Key factors contributing to the continuing disparity in the health status between minority and non-minority Americans are the lack of access to adequate health care and an insufficient number of adequately trained health professionals serving minorities and economically disadvantaged populations.

I, along with many others, am disturbed that the U.S. infant mortality rate continues to be worse than that of nearly every other industrialized country in the world. The rate within our black community is more than twice that within our white community. The 1992 budget requests \$5 billion to continue our efforts to reverse this tragic statistic. Included within this total is \$171 million for an initiative that targets funds to communities suffering from the highest rates of infant mortality in order to remove the barriers that prevent pregnant women and teenagers from receiving prenatal and perinatal care for themselves and their infants. There is still much work that needs to be done in this area; the additional funds requested are critical in enabling us to save more lives.

Additionally, the 1992 budget request of \$170 million represents more than a 28 percent increase in our efforts to train health professionals who are interested in serving minority and low-income populations. Prominent elements of this initiative include significant expansion of the National Health Service Corps recruitment program, recapitalizing the Health Professional Student Loan program, and the establishment of a new Federal construction program to enable historically black colleges, universities, and similar institutions to improve their research infrastructure and increase their competitiveness for Federal research funds.

Of equal importance as providing access to health care is preventing disease. Throughout HHS, we are seeking more than \$7 billion for prevention activities, a 9 percent increase over 1991.

Breast cancer remains one of the leading causes of death for women aged 35 to 54. Early detection and diagnosis are key elements to combating these preventable deaths. The 1992 request includes \$50 million to assist States and local health departments in offering breast and cervical cancer screening programs for low-income and disadvantaged women, an increase of 71 percent compared to FY 1991. Additionally, for women over 65, mammography screenings are now available as a covered service under Medicare.

Our prevention effort also seeks \$258 million for child immunizations, an increase of \$40 million or 19 percent over 1991. Under the leadership of the Centers for Disease Control, many childhood diseases, such as tetanus, diphtheria, and polio have been brought almost entirely under control. However, outbreaks of other childhood diseases, such as measles, mumps, rubella, and pertussis still exist, particularly among pre-school, inner-city children. These resources will focus efforts to remove barriers currently hindering delivery of immunization services to poor and disadvantaged children.

Recently, the Centers for Disease Control announced that over 100,000 Americans have died from AIDS. We must continue both our research and education efforts to reach all Americans with understandable and accurate prevention information. In 1992, AIDS research, prevention, and education efforts throughout the Public Health Service will receive almost \$2 billion, a 50 percent increase since I took office.

Drug abuse continues to extract too high a toll on our children, on our families and on our society as a whole. We have requested an increase of \$108 million for drug abuse treatment, research and prevention efforts throughout the Alcohol Drug Abuse and Mental Health Administration. Included in this total is \$99 million to expand the overall drug abuse treatment capacity of the Nation. Resources will be focused in areas where the current drug abuse problem far outstrips the capacity to provide treatment services. The total funding for drug abuse research, prevention and treatment activities within HHS is \$2 billion, an historically high level of support.

Almost a third of the discretionary expenditures for HHS--or nearly \$10 billion--are devoted to the biomedical and behavioral research efforts carried out by the National Institutes of Health and the Alcohol Drug Abuse and Mental Health Administration. The 6 percent requested increase of \$581 million will fund ongoing research in the prevention and treatment of diseases such as

cancer, AIDS and other sexually transmitted diseases, heart disease, and stroke. This budget directs funds towards a variety of initiatives, including efforts to map the human genome, developing drugs to treat people suffering from mental health disorders and drug and alcohol addiction, and re-building the research infrastructure on the NIH campus.

As a result of a growing national concern over both the quality and rising costs of health care, the Agency for Health Care Policy and Research was created one year ago to organize and support research studies focused on improving health care delivery methods. The budget for 1992 includes \$122 million, an increase of 6 percent over 1991, to undertake a wide variety of projects that will ultimately improve the patient's outcome.

I am committed to ensuring the quality of service provided to the American public through the large entitlement programs administered by this Department--Social Security, Medicare, and Medicaid. In recent years, budgets for both the Social Security Administration (SSA) and the Health Care Financing Administration (HCFA) have grown faster than inflation. As the beneficiary population grows in the future, it will put additional pressure on us to develop more efficient and effective ways to manage within the available administrative resources. This year, we were faced with difficult choices in managing within the constraints of the Budget Enforcement Act. The requested funding

is adequate to meet the basic mandates of these agencies. HCFA contractors will pay Medicare bills within the statutory time frames. SSA will focus its resources on processing claims applications and maintaining service levels. However, in some areas, there may be slow downs.

However, we are examining options for both SSA and HCFA to develop strategies for finding the most cost-efficient ways to provide service to the people who depend on us. SSA is developing a long-range strategic plan which will define service requirements, means to increase productivity and efficiency, and, in general, provide a picture of how SSA will deliver high quality service to the American public. HCFA is actively exploring ways to improve the uniformity, efficiency, and performance of Medicare contractors, including a review of alternatives to current contractor arrangements.

We are requesting a \$232 million supplemental appropriation for 1991 for the SSA to provide administrative resources to enable the Agency to carry out the additional work required as a result of the Supreme Court decision in *Sullivan vs. Zebley*. As funds were not included in the regular appropriation for this purpose, a supplemental appropriation is needed in order to meet the additional work demands.

As you are well aware, the Budget Enforcement Act of 1990 established absolute spending limits for all discretionary programs. In order to stay within the prescribed ceilings, we propose the following spending reductions.

The budget requests \$1 billion in funding for the Low Income Home Energy Assistance Program (LIHEAP). This amount is \$585 million less than the FY 1991 level. LIHEAP was created as a temporary program in the late 1970's in response to the energy crisis. These reductions reflect the fact that LIHEAP was never intended to meet the entire home energy costs of low-income households, but rather to supplement assistance available through other Federal and state programs.

The Community Services Block Grant and related discretionary grant programs are proposed for elimination in FY 1992. This would represent a savings of \$425 million. This program was initiated in FY 1981 to assist in establishing an infrastructure for improving services to low-income individuals and families. Since that time, basic reforms have been institutionalized and increased funding has been provided for activities such as employment services through the JOBS program and child development through Head Start and the Child Care and Development Block Grant.

The budget also proposes a reduction of \$186 million in funding for the Health Professionals Training Program. This represents a common theme throughout the budget of focusing resources towards programs that target minority and disadvantaged populations and away from broad-based categorical health professions programs.

In conclusion, we have endeavored to balance the competing demands of providing for the vast and varied health and income security needs of this Nation while staying within the absolute fiscal constraints defined by the Budget Enforcement Act of 1990. The programs administered by the Department of Health and Human Services touch Americans throughout their lives, providing essential prenatal and child care for low-income families, ensuring that all children start school on equal footing, advancing our scientific knowledge of disease prevention and treatment methods, and providing financial support for our elderly citizens. This budget reflects our strong commitment to ensuring the health and well-being of all our citizens. I look forward to working with you for its enactment.



DR. LOUIS W. SULLIVAN

Secretary of Health and Human Services

Louis W. Sullivan, M.D., was sworn in as secretary of health and human services March 10, 1989, by U.S. Circuit Judge A. Leon Higginbotham Jr. He was nominated by President Bush Jan 20, 1989, and confirmed by the Senate March 1, 1989.

As head of the Department of Health and Human Services, Dr. Sullivan oversees the federal agency responsible for the major health, welfare, food and drug safety, medical research and income security programs serving the American people.

Dr. Sullivan came to HHS from the Morehouse School of Medicine in Atlanta, Ga. In July 1975, Dr. Sullivan had become founding dean and director of the medical education program at Morehouse College. Since July 1, 1981, when the School of Medicine became independent from Morehouse College, he had served as its first dean and president. In April 1985, the Morehouse School of Medicine was fully accredited and on May 17, 1985, the school awarded the M.D. degree to its first 16 graduates.

Dr. Sullivan was born in Atlanta Nov. 3, 1933. He received a bachelor of science degree, magna cum laude, from Morehouse College, 1954; and earned his medical degree, cum laude, from Boston University, 1958. He did his Internship (1958-1959) and medical residency (1959-1960) at New York Hospital's Cornell Medical Center. After a pathology fellowship at Massachusetts General Hospital (1960-1961), Dr. Sullivan became a fellow in hematology at the Thorndike Research Laboratories of Harvard Medical School at the Boston City Hospital.

He was an instructor in medicine, Harvard Medical School, 1963-1964, and an assistant professor of medicine, New Jersey College of Medicine, 1964-1966.

In 1966, he became co-director of hematology at Boston University Medical Center. From 1966 to 1975, he was, successively, assistant professor of medicine, associate professor of medicine and professor of medicine at Boston University School of Medicine. During 1972-1975, he also was co-project director and project director of the Boston Sickle Cell Center and director of Hematology at Boston City Hospital.

Dr. Sullivan returned to Morehouse, his alma mater, in 1975 as professor of biology and medicine.

He is a member of the American Medical Association, the National Medical Association, Atlanta Medical Association, Medical Association of Atlanta, Medical Association of Georgia and the Georgia State Medical Association. He has been certified in internal medicine and in hematology. His research interests are in hematology.

Dr. Sullivan was the founding president of the Association of Minority Health Professional Schools. He is a former member of the Joint Committee on Health Policy of the Association of American Universities and the National Association of Land Grant Colleges and Universities.

Professional honors received by Dr. Sullivan include election to Alpha Omega Alpha Honor Medical Society in 1957, election to the American Society of Clinical Investigation in 1970, to Phi Beta Kappa in 1974, to the Institute of Medicine (National Academy of Sciences) in 1975 and to fellowship in the American College of Physicians in 1980. From 1985 to 1987 he was vice chairman of the Commission on Health and Human Services of the Southern Regional Education Board.

He served as associate editor of Nutrition Reports International, 1969-1973; on the Editorial Board of the American Journal of Hematology, 1975-1977; and on the Editorial Board of the Journal of Medical Education, 1977-1978. He has served as consultant and adviser to numerous organizations and agencies including several in HHS' Public Health Service and for the Veterans Administration. Prior to becoming Secretary, Dr. Sullivan was a member of the National Cancer Advisory Board of the National Cancer Institute, National Institutes of Health. He is a member of the boards of Friends of the National Library of Medicine and the Boy Scouts of America. He has been a member of the Atlanta Rotary Club since 1977.

Other honors received by Dr. Sullivan include: Boston University Alumni Award for Distinguished Public Service in 1985; Honoree of the Year of the State Committee on the Life and Health of Black Georgians in 1983; the Drum Major Award by the Southern Leadership Conference in 1982; establishment of the annual lectureship at the Morehouse School of Medicine in his honor in 1980; the Outstanding Alumnus Award from New York University's Cornell Medical Center in 1984; honoree of the National Association of Minority Medical Educators (NAMME) for outstanding contributions to the education of minorities in medicine in 1984; the first Martin Luther King Visiting Professorship at the University of Michigan in 1986; the Equitable Southeastern Regional Black Achievement Award for Education in 1986; and the Atlanta Urban League Award for Outstanding Community Leadership in 1987. He was a member of then-Vice President George Bush's official 12-member delegation to seven African countries in mid-November, 1982.

Dr. Sullivan and his wife, Ginger, have three children.

March 10, 1989

Mr. NATCHER. Thank you, Mr. Secretary.

Mr. Secretary, as you well know, the Budget Committee is now holding hearings on the budget proposals for fiscal year 1992. When we receive our 302(b) allocation, sometime in the next six or seven weeks, we are hoping to base our budget on the suggestions they make.

Although it is not binding, the Budget Committee recommends amounts for the Subcommittee in health and education. When they hold hearings and when they mark up their bill, the Budget Committee generally feels that health should have more money and education should have more money. A lot of people in the House will listen to them.

We are glad to hear they are cognizant of the fact that we ought to have more money for health and more for education.

And it helps us when we go to the big chairman who always stays with us, Dr. Sullivan. My big chairman, I am sitting right next to him now, and occasionally I ask him how he feels. And anyway, he wants me to ask him about every two weeks, Mr. Secretary. But anyway, he always stays with us. He knows, like every Member of the House and the Senate, that here is where we ought to spend our money, in the calendar year of 1991 on into the future, health and education.

Assuming now under our section 302(b) funding that we are able to obtain additional funds, and that the suggestions are made, we will be talking to you, Mr. Secretary, as we go along, about where some of this additional money should go.

And, as always, you will assist us and make suggestions and help us, assuming now that it doesn't violate any of the principles downtown as far as OMB is concerned.

NIH INCREASE FOR 1992

I think if you go back and check the records, you will find that the budget you have submitted to us this time carries the largest increase for the National Institutes of Health at any time since the Institutes started, and that is a good sign, Dr. Sullivan.

NIH GRANTS

Now, that is not the largest amount that we have carried in bills, but this is the largest amount that has been submitted to our committee—to the Appropriations Committee all down through the years for the National Institutes of Health by way of an increase.

We appreciate it.

The number of new grants was down, as you will recall, to about 4,800 last year, and we started with a right difficult budget from the standpoint of figures and so forth, and 4,800, of course, is not near enough. The committee added almost \$1,000,000,000, as you recall, to the NIH budget in 1991 to try to deal with some of the problems that we were confronted with by virtue of not having sufficient funds in the beginning.

At the same time, we stated, and you agree, that the funds should be effectively and efficiently expended. You recall we included a cost management plan in the House and the Senate reports last year.

Generally speaking, Mr. Secretary, how do you feel about the cost management plan that we suggested and so forth? How do you feel about it?

Secretary SULLIVAN. Mr. Chairman, we have been working with officials within the Public Health Service and NIH on the cost management plan, a number of specific recommendations have been developed to ensure that we utilize our funds more efficiently, and we provide strong oversight.

Generally, I am quite pleased with the recommendations that are coming primarily from our NIH administrative staff.

Mr. NATCHER. Are you generally satisfied with the mix between numbers of grants, length of grants and average cost per project?

Secretary SULLIVAN. Yes.

Mr. NATCHER. With the mixes?

Secretary SULLIVAN. Yes, we are, Mr. Chairman.

Among the things that our committee recommended is that we have as a goal an average of four years for each grant, and that we try to give greater stability to our grant numbers.

We also suggested less downward negotiation of grants so that investigators would be able to plan more carefully and with greater assurance about the dollars that they would have in outyears from the award.

The recommendations of the Public Health Service will address the problems and the unevenness of past years' research grants.

We are now, I believe, up to around 5,700 to 5,800 new and competing grants, and that is, we feel, an appropriate mix with our support also for centers. We are going to continue to work to increase the number of research trainees at the National Institutes of Health. We have not been successful in getting that up to the level that we would like to have, but we are moving in the right direction, and overall, I am very pleased with the balance.

Mr. NATCHER. Just generally, Mr. Secretary, how much money would we need to add to the bill for 1992 for NIH if we wanted to fully fund the second year of this plan, including 6,000 new grants? If you don't have that figure, place it in the record for us, generally speaking.

Secretary SULLIVAN. I will be pleased to get that figure back to you, Mr. Chairman.

[The information follows:]

NATIONAL INSTITUTES OF HEALTH COMPARISON OF FISCAL YEAR 1992 PRESIDENT'S BUDGET WITH
CONGRESSIONAL FINANCIAL PLAN FOR NIH ¹

	Fiscal year—			Increase: Plan over President's budget
	1991 current estimate	1992 President's budget	1992 estimate cost congressional plan	
Research project grants:				
Noncompeting	\$3,317,511	\$3,639,266	\$3,651,684	\$12,418
Competing	1,180,122	1,253,537	1,294,483	40,946
Total, RPG's	4,497,633	4,892,803	4,946,167	53,364
Number of noncompeting	15,401	16,033	16,033	
Number of competing	5,785	5,785	6,000	215

NATIONAL INSTITUTES OF HEALTH COMPARISON OF FISCAL YEAR 1992 PRESIDENT'S BUDGET WITH
CONGRESSIONAL FINANCIAL PLAN FOR NIH ¹—Continued

	Fiscal year—			Increase: Plan over President's budget
	1991 current estimate	1992 President's budget	1992 estimate cost congressional plan	
Total number of RPG's.....	21,186	21,818	22,033	215
Research centers.....	713,495	746,336	754,592	8,256
Number of centers.....	670	671	670	—1
Research training.....	306,386	314,638	330,110	15,472
Number of trainees.....	12,178	12,318	12,604	286
All other research.....	2,590,538	2,716,984	2,739,753	22,769
NIH facilities (non-add).....	(168,687)	(104,125)		
Total, NIH.....	8,108,052	8,670,761	8,770,622	99,861

¹ Excludes buildings and facilities.

CONGRESSIONAL PLAN ASSUMPTIONS

Fund 6,000 new and competing research project grants (RPGs) in 1992.

The increase in average cost of RPGs over 1991 levels will be limited to the Bio-medical Research and Development Price Index (BRDPI), which is 5.76 percent for fiscal year 1992.

Total budget for research centers is increased over 1991 at a rate equal to the 1992 BRDPI.

The number of research trainees supported will increase by 3.5 percent over 1991.

Stipends for research training will increase on average by 4.0 percent.

Budget for all other NIH activities (excluding facilities) is increased over 1991 at a rate equal to the 1992 BRDPI.

Amounts exclude funds for NIH buildings and facilities.

NIH GRANT COSTS

Mr. NATCHER. Now, Mr. Secretary, as you know, the average life cycle cost of a grant approved 10 years ago was less than \$400,000. Today, it is almost \$900,000. Do you believe these costs have been sufficiently managed by the National Institutes, just generally?

How do you feel about it?

Secretary SULLIVAN. We have been concerned, Mr. Chairman, about the inflation in our research grant programs. Part of the financial management plan I mentioned is to bring inflation under control.

A significant part of costs are difficult to control such as equipment, and supplies. We are working to have a greater degree of control over the rate of inflation, and I believe we are going to see improvement in the coming years.

Mr. NATCHER. Now, Mr. Secretary, how much of the 1992 request for the National Institutes of Health is expected to be paid as indirect costs?

Secretary SULLIVAN. That figure is around \$2,000,000,000 out of a total of, I believe, \$7,000,000,000, some \$2,000,000,000 would be for indirect costs.

One of the things I would like to add, Mr. Chairman, as you know, we are expecting to have Dr. Bernadine Healy confirmed soon as the Director of NIH. She had her confirmation hearing last week, which went extraordinarily well. One of the first responsibil-

ities I will give to her is to look at the issue of indirect costs at NIH.

Mr. NATCHER. Mr. Pursell, I yield to you.

Mr. PURSELL. Well, I was out at NIH yesterday, and spent all day out there, 9 until 6. I was certainly impressed with our programs and a couple exciting developments that struck me. Aside from all the breakthroughs in research there was something I have been interested in for a number of years, and that is the way we take research and deliver those services to the urban and rural areas.

Dr. Fauci said that in his department, he is developing guidelines which will establish criteria for approval of Federally funded research programs. There must be some guidelines that would encourage those faculty members and researchers to have initiatives that would deliver the research services, whether it is infant mortality, AIDS education, prenatal education. These are social problems more than technologically solved problems.

We want to put these research advances in communities of big cities, Detroit, San Francisco, New York, Cleveland. I am very impressed with some of the researchers who are beginning to look at delivery of services to match up with research so they begin to interface in those communities.

INFANT MORTALITY

I worked to set up an infant mortality clinic in my district last year. We raised private funds, the Kellogg Foundation made a contribution, we got a grant from our Department, and we asked the city and county for money.

We put together \$1,000,000 to establish a clinic, midwives and nurses. As well as doctor. We are going to address the issue of infant mortality to a county 40 miles from a university, where mothers could not get access to care and education and health.

I use that as an example delivering such services. Those of us who have been former State Senators years ago remember the methadone clinics. We had 22 in the City of New York. I toured and saw those facilities.

As we get into these kind of programs in delivery of services, and we are going to do one with one of your 10 infant mortality projects in D.C. Dr. Alexander said yesterday they will be using the city's services, the public health facilities, the infrastructure within the city to work with NIH in setting up a comprehensive infant mortality clinic, or however that is defined.

I am trying to think through where our public health services end up in a given urban area. We need education and the Head Start and other such programs that deal with children, as well as mothers and fathers.

So, I guess I see an evolutionary change of promoting research into a local urban setting where it is definitely needed. I am excited about that, but I am hopeful we think through the delivery of services so it isn't fragmented to such an extent it is not effective.

Secretary SULLIVAN. Yes, Mr. Pursell, I would fully agree with you. We have people coming not only to our major teaching centers from all over the country and the world.

When it comes to our ability to deliver very sophisticated medical care, we are unexcelled; where it appears we have fallen down has been in organizing so that all citizens have equitable access.

You mentioned you had problems having a county 40 miles from the university where you have access to care, even more startling is here in the District of Columbia, where we have four medical schools, Georgetown, George Washington, Howard, and the Armed Services Medical School, and one of the highest physician ratios to population in the country; we have also the highest infant mortality rate.

Factors that we know which contribute are individuals who don't have insurance, and services are not available where some people live.

We also have to be concerned about the people who are on drugs, who are not using those services, and certainly mothers during pregnancy. The mothers who smoke have a high incidence of low birth weight babies, which contributes to infant mortality.

I mention all that to say, we have assumed in the past that if we have the services, and if we had the technology, everything would automatically follow. That is not the case, we have learned a painful lesson. We have to learn how to couple these services with the population.

There are several Agencies that will help us to do that. First of all, our Agency for Health Care Policy and Research, our newest agency in the Department, is helping to develop practical guidelines and to evaluate a number of patient procedures.

We also are committed through our Health Care Financing Administration to a larger role for managed care through HMOs, PPOs, and similar structures: so that Patients will receive comprehensive, coordinated care, as well as preventive services, and costs will be controlled.

We are also emphasizing training of more primary care physicians. We have enough ophthalmologists and anesthesiologists, but we don't have enough family physicians or general internists.

Our reimbursement system has continued to bias young people coming through the system towards a super-specialty. We are working through our physician payment reform that we are now implementing, that the Congress passed last year, such things as a rearrangement of the fees paid to primary care physicians versus specialists, as well as bonus payments for physicians of up to 10 percent who settle in medically underserved areas.

All of those are designed to address how the system works. Our scientists are out learning how we can get AIDS education more effectively into the community. We awarded about a year ago some 28 grants to community-based organizations to get more minorities, more women, more individuals on drugs, into the system for AIDS education and treatment, because we are seeing too few of these individuals in our regular system.

Mr. PURSELL. Can you see the network—like I say in Detroit or Cleveland, anywhere, a network of many clinics and primary care physicians and a combination of a lot of primary preventive efforts, they are both medical and educational, working with schools?

Secretary SULLIVAN. Very definitely.

INFANT MORTALITY PROJECTS

Mr. PURSELL. If you look at what Schwarzkopf did in terms of Desert Storm, he had a mission and he put the tanks in the right place and soldiers in the right place, and was very successful. We have to deliver those services in the right place and have sort of a community united front for a mission, specifically for good delivery of services.

When I watch the D.C. project, if this kicks off and starts down that road, as one of these 10 projects, I think these demonstration projects will be good. We will see what works and doesn't work in the nine other cities as well as the District of Columbia.

I don't know if that is enough money, \$439,000,000—

Secretary SULLIVAN. \$171,000,000 is what we asked for totally. That is to be fully funded next year. We wanted to start this year with \$57,000,000 by reprogramming monies.

Mr. PURSELL. What did you put in?

Secretary SULLIVAN. We put \$25,000,000 in the supplemental. If we can get the additional dollars which on the Senate side they are looking at, that would relieve the pressure to reprogram.

Mr. PURSELL. Would that jump-start the 10 targeted infant mortality programs?

Secretary SULLIVAN. Yes, it would.

Mr. PURSELL. Dr. Alexander didn't seem to think they had really started the coordination on that project. We don't want to get the cart before the house, though.

Secretary SULLIVAN. Let me say this: First of all, just so everyone will know. We would certainly expect the District of Columbia to be one of the applicants for these 10 projects, but whether they are successful or not will depend upon the quality of their application.

We haven't finished developing the criteria, but they will include such things as urban and rural areas that have an infant mortality rate that is 1.5 times the national average. These are areas of high incidence, and a geographic entity that is definable, for evaluation so that we would not only see what happened at the end, but also be able to tell which components of that program actually were responsible.

The idea is to have information that we could then transfer to all of the country and would justify the expenditure of the dollars.

Mr. PURSELL. I just hope in closing here, we do it comprehensively so we include the rural areas as well as the targeted areas, because percentage-wise, mortality rates are high in some rural areas as well, at least in my State.

I believe we are targeting scarce dollars in the high problem areas, and I am happy to see that. I want to be sure we don't close off other opportunities to address the infant mortality problem. We will take a look at that block of money and see if that answers our question.

I congratulate you on your initiative. Thank you.

Mr. NATCHER. Mr. Stokes, I yield to you.

Mr. STOKES. Thank you, Mr. Chairman.

Mr. Secretary, nice to see you again, and welcome back before this subcommittee.

MINORITY HEALTH

This past year, you were very effective in working with Congress in the passage of the disadvantaged minority health bill. Subsequent to its passage, this subcommittee funded that bill initially in the amount of \$20,000,000.

I wonder if you could give us any assessment as to what has been done with the program thus far, and what request you are making relative to that legislation in this bill?

Secretary SULLIVAN. Yes, thank you very much, Mr. Stokes.

As you know, we are committed to the minority health initiative, because when we look at our population and some of the data that I have just been talking about, we see very startling statistics in our minority community.

So, for that reason, I have been committed to address that head-on, both from the standpoint of providing more training opportunities for minority health professionals, and from the premise that those individuals are more likely to settle and practice in those areas, as well as providing scholarship and other support for institutions that have a high minority population.

We have requested a \$31,000,000 increase for minority health programs this year. I am very pleased with the response that I have received from the medical education and health care community on this initiative that was passed with your leadership.

You will note that in the portion of our budget for health professions education, we are emphasizing the training of disadvantaged and minority students, because that is where the need is greatest.

Mr. STOKES. I am pleased to see your new initiative with reference to infant mortality. I represent, as you know, the east side of Cleveland, Ohio. Figures released this past week told us that the rate in my District is about 21 babies per 1,000, which is twice the national rate.

It is my understanding under your initiative, you are going to target 10 cities with high infant mortality rates. Can you talk about that program a little bit, and give us some idea where you plan to try and locate the centers and so forth?

Secretary SULLIVAN. Yes, Mr. Stokes.

There will be 10 areas, but we anticipate there will be a mix of urban areas and rural areas, large cities and smaller communities, and even the possibility of portions of cities as well.

In other words, you will see that the geographic criteria are quite flexible, for example, it can be an entire large city, or even a medium-sized city—as long as there is a problem. We want to have data at the end of this demonstration that would apply to the entire range of settings in the country. We will be looking at applications for areas that have an infant mortality rate that is approximately 1.5 times the national average or greater, and areas that have been resistant to prior efforts. We will look at the quality of the application which can be from either a governmental unit or a private agency, as long as that unit has the support of the community. We must have evidence in the application that there is community support and involvement which would argue for success, at least in carrying out the demonstration.

So, the criteria established will ensure variety. Since this is a demonstration, the evaluation mechanism's purpose is measurement of what we learn, which can reduce infant mortality. We are confident that we will learn major ways to organize our services effectively.

LEAD BASED POISONING

Mr. STOKES. Mr. Secretary, this committee has for some time been concerned about lead poisoning, particularly as it relates to minority inner-city youth. Last year, during the testimony that we received from CDC, we learned that what we are finding is when you take these children out of these inner-city homes that they inhabit, public housing and so forth, treat them for lead-based paint poisoning, then bring them right back into the same environment, the same problem occurs all over again.

One of the things we directed CDC to do was coordinate its lead testing program with HUD's Public Housing Abatement Program. Can you tell us whether or not anything has been done in that respect?

Secretary SULLIVAN. Yes, Mr. Stokes, I am pleased to report to you that in our budget, we have doubled the funds for lead poisoning, prevention and screening to \$15,000,000, but beyond that, we have developed a task force involving my Department, HUD, and the Environmental Protection Agency, to attack this problem.

You are quite correct in that if we put the children back into the same environment, we are indeed courting disaster. We now know about levels of lead in the blood that a decade ago were thought to be relatively harmless.

We have the potential for impairing the physical and intellectual development of our children in a significant way by exposure to lead poisoning. Our plan is to work with HUD and EPA to rid the environment of lead when we find children are exposed to high levels.

We are taking that discreet approach because it is obvious to all of us that lead is so pervasive that the dollars required to rid our old housing would be prohibitive.

But if we concentrate on those areas or that housing where children are, that will begin the process of making the environment safer for our children.

NIH MINORITY HEALTH PROGRESS

Mr. STOKES. Mr. Secretary, my last question addresses a concern I have had for several years about the National Institutes of Health. I have sat on this subcommittee now, I guess close to 20 years. My good friend, Joe Early here, sat next to me maybe 15, 16 of those same years.

Year after year, he has had to sit here and listen to me ask pointed questions of NIH personnel, different heads, about why we are making so little progress in eradicating the disparity between white and minority health care in the United States.

Invariably, when NIH officials come before us from all the various divisions, they agree with me that Secretary Heckler's Task Force Report pointed to glaring racial disparities in health care:

high blood pressure, stroke, cancer, diabetes, cardiovascular disease, homicide, and many other areas. Rather than seeing improvement, for the last two years, black males are decreasing in their life expectancy rate, rather than increasing.

One of the things I discovered last year, when the Institute Directors came before me and professed concern about all these areas and said they really want to do something about it, and that they were beginning to do some research in some areas, when I inquired into what percentage of their budget in each of these divisions was allocated to problems related to blacks and minorities, I found that percentage to be relatively minuscule.

It would seem to me, obviously, if you are not putting the Federal dollars into the research that goes into training to discover the basis and reasons for these disparities, then obviously nothing will ever be done about it, at least not to any measurable degree.

As Secretary of HHS, with NIH under your jurisdiction, and knowing that long before you went to that Department, you sat at this table and talked about the same type of problems that I am enunciating to you in this capacity, I guess I am wondering if you have had an opportunity to look at NIH from that perspective, and whether or not over the next 20 years I sit here, I can expect to see some progress?

Secretary SULLIVAN. Well, Mr. Stokes, I guess my first answer to you is I am in the briar patch now, because I have expressed to my colleagues at NIH my personal commitment to seeing that that agency, as well as my entire Department, is more responsive and effective in addressing health concerns, both for minorities and women.

And let me add a couple of things here in this regard. It will be a proud day when Dr. Bernadine Healy is confirmed as the Director of NIH. She will be the first female Director of NIH in the history of that body, her qualifications are unquestioned.

She is a first-rate scientist, and an excellent administrator. She was trained at leading institutions around the country, such as Johns Hopkins. Dr. Healy has sat on the Board of the Visiting Committee for the Harvard Medical School.

She shares with me my concern regarding minority health. We have also established an Office for Women's Health Research at NIH because over the years, perhaps inadvertently, women were excluded from clinical trials and elsewhere.

With Dr. Healy as the new NIH Director, once confirmed, I am sure she will bring sensitivity and leadership. Secondly, we have created an Office for Minority Health in the Office of the Director. We have already filled that position: Dr. Ruffin was recruited a few months ago from the University of North Carolina. His role is to serve as an ombudsman at NIH and to look at issues affecting minority health.

Our Office for Women's Health is being headed in an acting capacity by Dr. Ruth Kirchstein, who is serving as Director of our National Institute of General Medical Sciences. She and Dr. James Mason co-chair the Committee for Women's Health at NIH.

Mr. STOKES. Thank you.

Thank you, Mr. Chairman.

Mr. NATCHER. Mr. Weber, I yield to you.

Mr. WEBER. Thank you, Mr. Chairman.

Mr. Secretary, it is good to see you again. Mr. Pursell and I were talking. We agree very much with the chairman, anything named after Silvio Conte should have an adequate size plaque. If you have already wasted one, and it is a little too small, you can use it and name something after Carl Pursell or myself.

You could have the Pursell Utility Room or the Weber Laundry Chute, that is fine.

RURAL HEALTH CARE

For Conte, it better be big.

Mr. Secretary, I would like to ask you some questions about rural health care. I want to begin by thanking you for the good, cooperative attitude that the Department has toward the Rural Health Care Coalition here in the House of Representatives.

I think that is one of the more aggressive coalitions or caucuses that exist in the House, and we appreciate your having worked closely with us. It is not to say we necessarily agree with every decision the budget may indicate. I would like to talk to you about some of those decisions.

To begin with, one of our top priorities has been and has to be focusing on personnel shortages in rural areas. This really hit home very hard this last year. My wife had a baby in October, and we thought of moving back to my hometown just before the election, and having the baby there, and staying there for a while afterwards.

Finally, we could not do it, because in my home county, there is no longer anybody to deliver a baby. In the place I was born and my father was born and my brothers were born and my wife was born, we could not have our child delivered; we had to drive 30 or 50 miles to a hospital. That story is repeated in a lot of places in rural areas, and it is not just child delivery, it is all sorts of services.

Of course, a lot of that is directly linked to Medicare reimbursement. But we have some programs at the Federal level we have been trying to fund to deal with the shortages of different types of personnel, particularly the revitalization of the National Health Service Corps, which seeks to remedy 1,944 primary shortage care areas.

The President's budget talks about a fairly small increase, \$5,000,000, for the budget. I understand we have to fund 4,000 additional personnel if we were to bring all those up to snuff.

Has the Department done any kind of analysis that says with this rate of increase, how long it would take to actually remedy the bulk of the problem?

Secretary SULLIVAN. Well, Mr. Weber, it certainly would take a significant number of years. One of the problems we confront is the time it takes these individuals to complete their programs.

As you know, I am committed to expanding the National Health Service Corps. It is no secret I believe it was down-sized too far, and we have been working for the past two years to increase its size. The \$5,000,000 increase in the budget, will take it up to \$96,000,000.

The problem that we confronted while putting our budget together, was the range of competing needs. I am bothered by the fact that with 4,000 or so shortage areas, that we are projecting our ability right now to respond to only about 1,000 of those.

But we also have our loan repayment program in our budget, which would help both the numbers, and would actually place people more quickly, who are willing to work in a shortage area. This program would pay off portions of their loans, depending upon the length of time that they work in shortage areas.

The reality is that with our budget ceilings, with the whole host of competing priorities, we did increase the funding for the National Health Service Corps.

Mr. WEBER. Mr. Secretary, a second part of that problem then becomes, of course, the competition in terms of the distribution of personnel under the program, the thousand I think you said you might be able to fund.

It is sensitive because rural areas are concerned there might be a bias and criteria towards urban areas. Let me be candid with you.

A concern that has been expressed to us, that if the AIDS problem is the criteria in assigning Corps physicians, physicians would be almost exclusively in assigned areas of urban personnel shortages. We don't want to be left out of the game because of that.

Secretary SULLIVAN. Yes, Mr. Weber, we are concerned and sensitive to that. The reality is that actually 55 percent of our core physicians are assigned to rural areas. The criteria considers travel times to the nearest health facility, and the presence of other health personnel.

I think that the criteria which I would be happy to forward to you favors placement of core physicians in rural areas over urban areas.

Mr. WEBER. Fine, if you would supply that to me or my office I would appreciate it.

[The information follows:]

The National Health Service Corps (NHSC) places NHSC members in Health Professional Shortage Areas (HPSA) with the greatest need. To accomplish this, the Department has developed a Health Professional Shortage Area placement opportunity list. This list is developed in consultation with local communities, State agencies, Public Health Services regional offices, the Indian Health Services, and the Bureau of Prisons.

The National Health Service Corps Revitalization Act of 1990 provided explicit factors to be considered when determining the priority of HPSAs as placement sites. Sec. 103 (b) states that "In making a determination under subsection (a)(1)(A) of the health manpower shortage areas with the greatest such shortages, the Secretary may consider only the following factors:

(1) The ratio of available health professionals to the number of individuals in the area or population groups involved, or served by the medical facility or other public facility involved.

(2) Indicators of need as follows:

(A) The rate of low birthweight births.

(B) The rate of infant mortality.

(C) The rate of poverty.

(D) Access to primary health services, taking into account the distance to such services.

In making final decisions, the Secretary is given a certain degree of discretion to determine priority among sites. Current priority is attributed to sites which: include systems of care that coordinate the delivery of primary care services; have demonstrated record of sound fiscal management; or will experience a negative impact on its capacity to provide primary health services if not assisted by the NHSC.

RURAL HOSPITALS

Mr. WEBER. The second question or concern I have is the rural hospital transition grant program. I think Senator Durenberger was an author of the original legislation. It is a very important program—I am sure you know that the community hospital is more than a source of medical care, it is a focal point of a community's very existence.

In those smaller communities, particularly where the hospital's broad service function mission may not be justified, we are anxious to find new ways to assure the institution of long-term viability.

The rural health transition grant program, which we have used quite a bit in my state, has been very enthusiastically received by the hospitals that have participated.

Why did the budget seek termination of that program?

Secretary SULLIVAN. Well, Mr. Weber, as we look to that, there are several things that I would comment on.

First of all, the rural transition grants were two-year grants so we still will have many of those grants operative during this year.

We also are looking at a variety of additional strategies to assist health care in rural areas. For example, our Centers for Disease Control has, through the National Institute of Occupational Safety and Health requested \$20.5 million for a variety of programs for rural health and farm safety programs.

Injury from machinery, is one of the major causes of death on the farm. So we have a series of centers that are funding development of better strategies for safety on the farm.

We also are completing our plans as mandated by the Congress, to eradicate the differential reimbursement between urban and rural hospitals by 1995, which will also help with the problems of rural hospitals.

Clearly we recognize that it is going to take all of this to effectively address the problem of rural health care.

Mr. WEBER. I just want to ask one last question, because my time is up here. As you know, many of us in Congress pushed very hard for the establishment within your department of the Office of Rural Health Care.

We now have that office and its staff, but we are concerned. One of the things we wanted to see was that office have direct communication with HCFA, where we have most of our reimbursement problems in rural areas.

Have you set up or can you help us a little bit in understanding—do you have a formal relationship between the Office of Rural Health Care and HCFA, a process by which that office would provide input or solicit input from HCFA?

Secretary SULLIVAN. Yes, Mr. Weber, I think, the details, I will want to get back to you in writing. Let me assure you we do have very active communication between that office and our Health Care Financing Administration.

First of all, Dr. Mason, our Assistant Secretary for Health and Dr. Gail Wilensky, our HCFA administrator work together on a broad range of issues, including rural health care. Dr. Human, the Director of our Office of Rural Health Care, does have extensive

interaction with HCFA staff, but I will get back to you the specifics of how that interaction is formalized.

[The information follows:]

Six months after its inception, the Office of Rural Health Policy (ORHP) entered into a memorandum of understanding with Health Care Financing Administration (HCFA) regarding rural health. In addition to this formal linkage, the ORHP has had an individual from HCFA serving on staff for more than two years as primary liaison with the agency. The relationship between the ORHP and HCFA has been extremely favorable. The ORHP reviews all HCFA regulations which potentially affect rural communities, meets with HCFA regularly on significant rural health issues, and includes HCFA staff in an advisory capacity on PHS projects such as the Health Services Outreach Grants program and as participants in National Advisory Committee on Rural Health meetings.

Mr. WEBER. Fine. By the way, you mentioned Dr. Wilensky. We, the Republicans, had a conference up at Princeton and Dr. Wilensky came up and addressed the panel and was one of the stars of the show.

Thank you, Mr. Chairman.

Mr. NATCHER. Mr. Early, I yield.

Mr. EARLY. Thank you, Mr. Chairman.

Dr. Sullivan, on this first round of questions I want to touch on three things with you. A parochial situation, Africa and personal responsibility. I think you are aware of parochial matters.

MEDICARE PAYMENTS

I wrote you a letter on December 20 about an overpayment by the Federal Government to one of my cities of many dollars and also an underpayment to the city. Dr. Wilensky, that Benny just referred to, has been outstanding. But it is such a unique situation.

In my letter to you, I pointed out that, as soon as the city manager heard of the problem, he contacted the regional inspector general. He assigned responsibility, not to the City of Worcester, but to the management of HCA Group that was running the hospital; and to Blue Cross/Blue Shield, that should have detected the problem almost immediately with the first overpayment.

But it went on and on. The auditing firm did not catch it. I am sure the recoupment will come, but it will come from them and not the city.

Dr. Wilensky addressed a second problem to us, in the city hospital that treats our poor; it is totally for this reason, the poor, that we had to make some adjustments.

The city has done that, but they need an adequate cash flow. The city thought there was an underpayment which HCFA was in the process of auditing and which, I think, they have finished. It is going to show the city was underpaid by \$2.5 million.

For the city to be able to address the problem, Dr. Sullivan, we need some cooperation that that underpayment comes back to the city, and we can address what they are going to do. I just look for your cooperation.

As I said, Wilensky has been great and you have been available. That is all I will say about that letter I wrote to you on December 20; you got back to me and told me you were going to Africa.

Secretary SULLIVAN. Let me say I will be happy to get back to you to bring you up to date on this. I met with Dr. Wilensky about

that specific issue and I know she has been working very diligently on that.

[The information follows:]

The city of Worcester, Massachusetts recently announced its plan to sell or transfer Worcester City Hospital to the University of Massachusetts (UMass) Medical Center. The UMass Medical Center plans to convert the hospital to a sub-acute care facility. UMass asserts that it will not assume City Hospital's debts from before July 1, 1991, including \$14 million owed to the Medicare program as a result of taking double payments for treating Medicare patients. The City of Worcester has announced its plans to work with Congressman Early in an attempt to get HCFA to either "forgive" or extend repayment time on the \$14 million debt.

In an agreement reached last April, City Hospital has been paying interest only on the original overpayment amount. This agreement expired effective March 1991. In an attempt to reach agreement on a true repayment schedule, HCFA agreed to expedite the audit of the hospital's FY 1990 cost report to validate *underpayments* reported by City Hospital. Massachusetts Blue Cross has completed the audit and is prepared to issue a Notice of Program Reimbursement (NPR). The NPR shows that underpayments of approximately \$2.3 million were made to City Hospital. The underlying reason for the existence of these underpayments was an increase in the case-mix of City Hospital.

HCFA has a number of options for recouping the overpayment and satisfying the underpayment. These include: (1) applying the total amount of the underpayment to the total amount of the overpayment and negotiate an agreeable repayment schedule; (2) applying part of the underpayment to the overpayment and pay the balance of the underpayment to the hospital and negotiate an agreeable repayment schedule; or (3) issuing the entire amount of the underpayment to the hospital and negotiate an agreeable repayment schedule. HCFA has agreed to a maximum of a 7 year repayment schedule. HCFA estimates that a 7-year straightline repayment of \$179,200 per month would be needed to retire the overpayment under the first option. Ironically, if HCFA released the entire \$2.3 million underpayment to the hospital, its monthly payments on the overpayment would increase by approximately \$34,000, placing an even greater burden on the hospital.

HCFA has recently learned that several surgeons have resigned from City Hospital, as well as the hospital's medical director. Due to these staff resignations, the patient census has dropped dramatically and the case-mix index has declined since the underpayments were made. HCFA is reviewing with the General Counsel's Office the steps it should take in the face of the likely closure of the hospital, particularly in light of the reports that UMass will not assume any debts of Worcester City Hospital. In the meantime, HCFA is immediately reducing the bi-weekly interim Medicare payments to the hospital to reflect the drop in discharges and case-mix.

Mr. EARLY. She has been working on it, but it is the cash flow issue that is critical for the city in order to do what it is going to do. The city is going to make a bold move that will irritate a lot of people in Worcester.

The poor people in the area are going to get treatment and the other things that are supposed to happen when you make tough decisions. We really need that to make that happen right now as far as resolving that underpayment to the city.

Doctor, you told Chairman Natcher that you went to Africa at the beginning of the year, right, during the holiday season.

AFRICAN HEALTH CARE

And in your opening remarks, you spoke about the disease threats over there, diseases that are no longer a threat in the United States; diphtheria, tuberculosis, et cetera. Are you going on making recommendations? We don't want to tell African nations how to run their country, but we should be given more in the way of medical supplies that can't be black marketed—that will get to the poor people you talk about.

Are you going to give us a specific recommendation about that?

Secretary SULLIVAN. What I have done, Mr. Early, I met with the President when I came back and gave him first, a verbal report and now, I have submitted a comprehensive written report to him that has a number of recommendations in it, and I would be pleased to share that with the Committee.

A COPY OF THE REPORT WAS FORWARDED

There are a number of recommendations that we made, such as the fact that the economies in many of these countries are fragile. We need to work with them to help strengthen their economies.

Also, one of the untold stories of change that is not adequately recognized here is the trend towards democratization on the African continent. The Ivory Coast is planning to have Democratic elections next year, so is Nigeria. Some changes in South Africa are under way, but other countries need to work toward Democratic reform.

The country of Zimbabwe, for example, is now committed to moving from a one-party state to a two-party state. I met with President Mugabe there, I had with me, Dr. Roskens, head of USAID. The other recommendation we made is to help them strengthen their primary health care system.

There are some things we can do in our department which we are already gearing up to do but others will need to have specific action, either from other parts of the administration or by the Congress. And I will be happy to give you a copy of that report.

Mr. EARLY. I have problems with foreign aid, Dr. Sullivan. I can't understand how they can have diseases that we have eradicated why we can't get that addressed.

The third thing I want to talk about is your comment on personal responsibility, partnership, et cetera.

I read your statement, and you are to be commended. You certainly identified the problems. You spoke to the white communities and said we have got a lot of problems. And you spoke to the minority communities and reiterated the same message.

You identified the divorce rate and the number of children born out of wedlock, et cetera as problems. And you really put the responsibility where it should be. But now that you have identified the problem and your approach to a long-range solution, what should we be doing right now?

I was very impressed with a statement in this morning's Post by Congressman Rostenkowski, and I want to quote from it. He is talking about children, your constituency. "There is a depressingly logical momentum here," he said. "Kids who start off on the wrong foot spend a lifetime trying to catch up. And they don't.

"Kids who don't have enough to eat tend to get sick. Kids who lack adequate medical care tend to miss a lot of school. Kids who aren't in class don't learn how to read. Teenagers who are illiterate tend to drop out of high school."

MINORITY INITIATIVES

You have identified what would cause for both the white and minority children. How can we have, as this committee heard earlier, an 80 percent dropout rate for minorities in urban areas? What do

we do in this budget? There isn't money to address that, Dr. Sullivan, as far as what do you want to do about that.

Secretary SULLIVAN. Well, thanks, Mr. Early. I agree with you that this is a serious problem that we do need to address, but we have several things in my budget that are focusing on that.

They include, for example, a \$90 million increase in our child welfare services. That is to prevent the child abuse and other problems that would lead to removal of the child from the home.

We also have our minority male initiative, a program initiated last year.

Mr. EARLY. How much money?

Secretary SULLIVAN. We are asking for \$3.5 million for that program for this year. This is for community based grants to provide mentoring, academic tutoring, and other activities for young people. We are taking advantage of a number of organizations in the minority community, itself such as Concerned Black Men. Our infant mortality initiative is something we also see as having an impact.

Mr. EARLY. Dr. Sullivan, I think that in your statement, where you identified the problem, you are also suggesting that money isn't the total cure, but we are not spending enough money on these problems, Dr. Sullivan. We want to get a dollar's worth for a dollar spent.

We are not spending enough when Congressman Rostenkowski says kids that can't eat tend to get sick. If these kids are dropping out of school, an 80 percent dropout rate, they are not getting school lunch.

You also said that for minorities, violence is a problem. There is a killing every night in Boston, Massachusetts. There is so much of it on the front page that it is not news anymore.

I don't see enough money in this budget to address that. I want to cooperate with you, but I am tired of Congressman Stokes having talk about what we are not doing. Tell me where the money is in your budget, Doctor.

Secretary SULLIVAN. I would be happy to get back to you. We do have funds throughout our budget to address that.

For example, our budget for child health and welfare services increases \$5 billion from \$39.8 in 1991 to \$44.5 in 1992, but it is in different programs. I would be happy to get the specifics of that back to you.

[The information follows:]

As in prior years, the FY 1992 budget includes funds for many programs from which minorities may benefit. While we do not track these program dollars by race, we know that programs such as Aid to Families with Dependent Children (AFDC), Head Start, Supplemental Security Income (SSI), Disability Insurance (DI), Medicare, and Medicaid provide much needed assistance to many of our minority citizens. In addition, we know that minorities also benefit from research performed at the NIH and ADAMHA, even when not directly targeted to a particular minority population. Together, then HHS programs provide billions of dollars annually to minority individuals and families to prevent sickness, hunger and family disintegration.

In addition to these programs, PHS has programs which attempt to specifically target remediation of the health and social concerns of minority populations. This includes health professions and research training opportunities, health services delivery, enhanced data collection on minority populations, targeted HIV/AIDS programs, and continued coordination of HHS programs and community outreach

through the Office of Minority Health. The FY 1992 budget request includes \$485 million for these direct PHS programs, an 11 percent increase compared to FY 1991.

Also, our Head Start Program is another example of a program that helps. That program had last year, the largest increase in its history, where we requested \$500 million for that program.

Mr. EARLY. Dr. Sullivan, do you know why Head Start funding is where it is? Because Congressman Stokes put in the money. He put the money in Head Start with the support of Mr. Natcher and Mr. Conte, for years.

It didn't come in from the administration whether they were Democrats or Republicans. There is not enough to come in this budget to address where you are putting the blame.

You are saying social responsibility; you are looking for partnership. There also has to be a little more money to address the problem, Dr. Sullivan.

Secretary SULLIVAN. I agree with you, Mr. Early, but let me say in the budget that came up in 1989, we asked for an increase of \$250 million. When the budget came up last year, we asked for an increase of \$500 million. This year, we are asking for an increase of \$100 million; that is \$800 million increase.

I can't account for what happened before we arrived, but what we asked for is the largest increase that has ever been asked for. I want to assure you this administration and this Secretary are concerned.

Mr. EARLY. We just had the Persian Gulf conflict. We ended the war in 43 days because we had smart bombs and smart weapons. You say you want to take the benefits of high technology. We don't have smart drugs and smart—we are not doing that. We are not making the commitment in your area that we made in Defense.

There is absolutely no reason why we haven't resolved the problem of sickle cell anemia, is there, Dr. Sullivan, except that we haven't made enough of a commitment to it? My impression—and you tell me if I am wrong—we haven't solved the problem of sickle cell anemia because we haven't made the financial commitment to it.

Secretary SULLIVAN. Well, I don't want to argue item by item with you, Mr. Early, but in a sense, I think almost any program could make an argument for more dollars. But it really is both dollars and the opportunity.

In other words, science moves on an erratic scale. If you look at it very closely over long-range, it moves in a fairly steady progression. That really depends on a lot of things making that possible, and it is really a process, both of the state of knowledge of the field, as well as the dollars that are available to invest in that.

I was, as you may recall, on the first National Advisory Committee for sickle cell program when it was first established in 1971. And, of course, we had great hopes then that we would make significant progress, and we did learn a lot about sickle cell anemia. And I think we know much, much more now than we knew then. But we still don't have that cure for sickle cell anemia.

Mr. EARLY. In the next round of questions, Doctor, I am going to go back to personal responsibility and about what is not in this budget. I want to stay within my ten minutes, but I really think

you made a bold statement to the minority community. I admire you for that.

I think a lot of the problem is not to throw a bucket of money at it. At NIH, scientist are spending too much time in renewing their grant, rather than concluding what the goal of the grant is.

Mr. Natcher doesn't throw money at problems, but I think that if we can get money for NIH, and reduce that dropout rate, Dr. Sullivan, it will help.

If we don't keep the young people in school, we are not going to solve the problem.

Thank you, Mr. Chairman.

Mr. NATCHER. Mr. Pursell, I yield to you at this time.

INFANT MORTALITY PROJECTS

Mr. PURSELL. Thank you. I want to thank the chairman because I do have another appointment in a few minutes.

When I was at NIH yesterday, I asked if there was a bust out there of Joe Early. We have a lot of building with appropriate names on it, but that bust ought to be in gold for the work he has done for NIH.

Are the 10 cities listed in the infant mortality initiative locked into cement or might we be able to add more cities to that list? Do we have the flexibility to broaden that?

Secretary SULLIVAN. To some additional areas?

Mr. PURSELL. Well, not within the current amount I guess. We would probably have to find an offset or some additional money if possible within the allocation, but if we went to 15 or 20, from a planning, management—implementation standpoint, would that be a serious problem?

Secretary SULLIVAN. No, we could certainly expand the number of centers if we had more resources. But as you know, with this, as well as other issues that we are concerned about, we are operating, under the constraints of the budget agreement.

And so therefore, we have had to establish priorities with the dollars that were available to us. And we felt that this was indeed a top priority that we needed to get started on, and this would be a way of starting while we continue to address many other needs in the Department as well.

Mr. PURSELL. You can't answer that question today, but I think the Committee would be willing to take a look at it from the standpoint of some expansion given the restraints and dollars and caps and offsets. We can do that, but I am very happy to know there would be some flexibility in that area to add in addition to the proposals.

Thank you, Mr. Chairman, and thank you, Dr. Sullivan.

NIH INDIRECT COSTS

Mr. NATCHER. Dr. Sullivan, we all see newspapers, and from time to time television programs, concerning the matter of indirect costs. Recently, there was one on television that didn't pertain to rates set by your department, but still of great concern to the people.

This is a matter that I know you are concerned about. It makes you wonder, from time to time, if the taxpayer is being taken care of when it comes to indirect costs, Mr. Secretary.

We know of our interest and your concern. Mr. Secretary, we both watched a program about this on television last week. It certainly wasn't good. It wasn't good at all. Mr. Secretary we both need to work on this problem.

NEW NIH DIRECTOR APPOINTMENT

Mr. Secretary, as you pointed out to the Committee, Mrs. Healy will soon be confirmed and will be Director of NIH. Why did it take so long to select a director?

Secretary SULLIVAN. It is a combination of factors, Mr. Chairman. First of all, I am concerned about the salary levels at NIH. I am pleased that there has been some improvement in the salary levels. This is one of the things that Mr. Conte and the other members of this committee worked with us on last year.

But even with the improved salary, we have to rely on recruiting people whose dedication is so great; and whose personal circumstances are such that they can afford to make the financial sacrifice that this often entails when moving from positions in the private sector to positions at the National Institutes of Health.

I think that also there was a question, unfortunately, that arose concerning qualifications for the NIH Director that did not sit well with the scientific community. A mistake was made by a personnel individual talking with one of the candidates without my knowledge.

When that happened, we informed the scientific community, in November of 1989, that the sole criteria for the NIH Director would be scientific competence and administrative capability.

I think all of us recognize that the process of background checks that are required for such appointments is such that it does slow the process down greatly.

Some of our potential candidates don't like that process because of the fact that, while it is intended to be a confidential process, it invariably gets into the press before even a formal offer is made.

All of those facts contributed to the delay. The background process for Dr. Healy, for example, took around five months or so, which is just incredible.

And here is an individual, as everyone noted in the Committee hearings last week, whose credentials are exemplary, and who will provide great leadership. These are things that individuals in the private sector don't have to suffer through.

So all of those factors concern me because they really make the position less attractive than should be the case. This is the leading biomedical research position in the world, heading a \$8, almost \$9 billion research agency and also directing the future of research around the world.

We are working to see what we can do to streamline that process in the future.

Mr. NATCHER. Many of the members in the House, as you know, are concerned about the Department's attention to the problem of breast and cervical cancer. We note in your budget you are pre-

senting you are requesting the full \$50 million authorized for screening programs, and that is good.

This was a matter we had up as the members on the subcommittee in the conference with the other side. We finally ended up with \$30 million in the 1991 bill.

Now, tell us, if you can, just generally, what you propose in the 1992 level of effort in all areas, related to breast cancer including research, as compared to 1991, just generally, Mr. Secretary.

Secretary SULLIVAN. Yes, Mr. Chairman. I am pleased with the support that we have gotten for full funding. This is one of those areas that I can assure you the President himself is personally committed to, and is aware of this figure.

This amount will almost double our capability. It represents a 53 percent increase over the 1991 amount. In addition to that program, which will be operating through our Centers for Disease Control, we also will have for our Medicare population, breast and cervical cancer screening. I believe that will amount to some \$350 million that will be available for them.

Mr. NATCHER. Mr. Secretary, as you know, this is for screening. Now we have in the House and in the Senate and all throughout the country a great many people who are also concerned about research on breast and cervical cancer.

As we go along, Mr. Secretary, if you will watch for us, as far as research is concerned, that will be of great assistance.

NIH DIRECTOR'S DUTIES

Mr. Secretary, will the duties of the new director of NIH be enhanced as recommended last summer by your advisers.

Secretary SULLIVAN. Yes, Mr. Chairman. Dr. Healy's duties will be enhanced in several specific ways. First of all, she will have available as the director of NIH a \$20 million discretionary fund which will give her the flexibility to move quickly on newly identified research needs.

Secondly, she will be meeting with me directly at least monthly to convey the needs of NIH, as well as the problems that she and others confront.

Thirdly, she will have a more significant role in the appointment of individuals to various advisory and review committees at the National Institutes of Health.

And, fourthly, she will play a significant role in developing the health research policy of the nation in her role as Director of the National Institutes of Health. The enhanced role of the Director of NIH, will give that position greater authority, prestige and the potential for greater leadership.

AIDS BUDGET

Mr. NATCHER. Mr. Secretary, the request for AIDS-related activities at the Public Health Service, as you know, \$1,950,000,000 which is about 3.5 percent above the 1991 level.

As you know, there are a great many people who believe we should be putting more money into these activities, and particularly into the Ryan White authorization. Others have argued maybe there is too much in here.

Are you satisfied generally with the amount as far as AIDS is concerned in the present budget before the Committee?

Secretary SULLIVAN. Yes, Mr. Chairman, I am. Because I would like to point out that our funding for AIDS has increased by 50 percent. Since 1989 NIH funding for AIDS is now comparable to all what we spend for cancer. Although, as has been pointed out by the many in the field, that many more people are effected by cancer and die from cancer than from AIDS.

But, more importantly, I have been told by my scientists at NIH that there is no major area of AIDS research that is not being funded. I think there is always, of course, competition between AIDS and other research efforts for specific grants, but there is no major area of research that is lying fallow. We are funding research for the development of vaccines, new drugs, enhanced immunologic procedures, behavioral research for prevention efforts, and greater epidemiological research through our Centers for Disease Control.

There have been major advances in our understanding about AIDS in a relatively short period of time and there will be more advances coming along. But, overall, we are pleased with the level of funding.

Mr. NATCHER. As you look into the future, in terms of the incidence of AIDS in certain areas of our country, do you think these communities can address these problems without additional Federal assistance, Mr. Secretary, in the places you and I know about where we really have the problem now as far as AIDS is concerned?

Secretary SULLIVAN. As you know, Mr. Chairman, our medicare and medicaid budgets, we are spending \$1.36 billion for AIDS or \$300 million more than fiscal year 1991. Along with the increased emphasis from the Ryan White Bill, is quite a significant amount from the Federal level to fund the AIDS problem.

SSA WORKLOADS

Mr. NATCHER. The Committee was pleased to learn, Mr. Secretary, that the \$100 million of the Social Security contingency was released, I believe, on Friday of last week. We continue to be concerned, however, that the 1992 budget request does not keep up with the anticipated workload.

For example, under your request, the number of disability claims pending at the end of 1992 will increase by more than 300,000 cases. Should the Committee approve a budget which projects a decline in service for the Social Security system? What do you suggest here, Mr. Secretary?

Secretary SULLIVAN. Mr. Chairman, this is one of those difficult areas because of the budget constraints, there is no question that the number of claims that our Social Security Agency is facing will increase.

Part of that we think is related to the economic downturn. We are working on a long-range plan that will be finished later this year which will help give us greater efficiencies with the dollars that we have available and help us in processing claims timely.

Mr. NATCHER. Mr. Secretary, just approximately how much money would we have to add to the Social Security request for 1992 if the Committee wanted to maintain service levels in all of the Social Security Administration programs? You might want to place it in the record.

Secretary SULLIVAN. Yes, I would be pleased to get a response back to you for the record, Mr. Chairman.

[The information follows:]

The FY 1992 President's budget for LAE represents a 9 percent increase over the FY 1991 enacted level and provides for a slightly increased FTE level. This increase reflects the President's recognition that resources are extremely limited government-wide, and that we are one of many Departments competing for those resources. We understand that increasing workloads and service demands will require prudent management of resources, and we have made the hard choices to allocate those resources in the most productive manner. We believe that SSA's Strategic Plan, currently under development, will help chart SSA's future course and ensure that its tradition of quality service continues.

You have asked how much money would need to be added to the President's FY 1992 budget if the Committee wanted to maintain service levels in all of the Social Security Administration programs. After revisiting our estimates, without financial constraints, we believe that \$4.7 billion total would maintain current service levels, and prevent deterioration of service below the FY 1991 level.

Mr. NATCHER. In the long run, what steps can be taken to make the Social Security and medicare systems more cost-effective as we plan for the large workload increases which we know are coming?

Secretary SULLIVAN. For fiscal year 1992, we will have 560,000 more beneficiaries in our Social Security program. And, of course, that adds to the overall workload, which we foresee increasing even in coming years.

We are working on a plan for improving the use of automation and other management tools. This will enable SSA to be more efficient in claims processing, while we work to address the budgetary pressures of the agency.

Mr. NATCHER. Mr. Early—Mr. Stokes, I yield to you.

PRISONERS WITH AIDS

Mr. STOKES. Thank you, Mr. Chairman.

Mr. Secretary, on the matter of AIDS, I am concerned about reports that larger and larger numbers of our prison inmates are now coming in to prison as a result of drug use and so forth, being afflicted with the AIDS problem. How big a problem is it and are we doing anything about it?

Secretary SULLIVAN. It is a significant problem that I would be pleased to get some specific information back to you, Mr. Stokes. The whole issue of prison health care is of concern. Unfortunately in the prison population the level of educational attainment is not as high as the general population.

The incidence of drug use, including IV drugs, is significant as well, and these are factors that are associated with the greater incidents of AIDS. The question of the quality of health care systems in our prisons is one that we have asked our Public Health Service to look at for us.

Many of our prisons, are under local jurisdictions, but we certainly want to see whether we can be helpful in improving the overall health care system.

The specifics of the AIDS problem, I will have to get that back to you.

[The information follows:]

On August 16 and 17, 1990, the National Commission on AIDS conducted site visits to correctional facilities in New York to gain a better understanding of issues confronting the Nation regarding HIV disease in Federal, State and local correctional facilities. The Commission's deliberations touched on issues related to overcrowding and its effects on correctional health care services, to prisoner access to clinical trials and experimental treatments, and to AIDS education and prevention efforts. The Executive Summary will be released as an interim report shortly. The full report, "HIV Disease in Correction Facilities", will be released to the President and the Congress within the next several months.

PEDIATRIC AIDS

Mr. STOKES. How about either the pediatric AIDS cases or the crack baby cases? In fact, a couple of weeks ago, I was out at Babies and Children's Hospital in Cleveland, Ohio, a hospital where I believe both you and President Bush have now been scheduled to come out to visit twice.

I guess it has been cancelled both times; but, I was out and took a tour to see what is happening with crack babies and these little children that will never have a chance in life by virtue of what has happened to them prenatally.

Are we doing much in that area? What are we doing?

Secretary SULLIVAN. That is a difficult problem, Mr. Stokes. I have visited a number of hospitals, neonatal intensive care units over the past year, and have seen a number of these babies in hospitals in Los Angeles, Orlando, right here in the District of Columbia, as well as in Fort Lauderdale and Detroit.

In spite of an expenditure of great sums of money for the care of these children, we are often at the end of that period left with a child whose future is greatly compromised.

In Detroit at the Henry Ford Hospital, I saw an infant that had been there almost two years in the intensive care unit and had difficulty with his breathing reflexes and needed further care.

The hospital bill was about \$2,000,000 at that time. There was no parent there, so that was a serious problem, which we have seen elsewhere, with other border babies.

I don't think we can really give you the dimensions yet of what this will mean, because we still are learning. The first wave of crack babies, are now in their early years in the school system, and we are receiving anecdotal reports of learning difficulties and behavioral problems, but I think we don't really have the full dimension of that.

We are targeting prevention from two standpoints. We have in our budget a proposed increase of \$100,000,000 for drug treatment programs, and a significant part of that, approximately \$30,000,000, is going towards treatment of pregnant women. At the Hutzel Hospital in Detroit, I visited one of the few facilities for pregnant addicts drug treatment. We do have a problem with adequate treatment slots for women during pregnancy.

But that funding through our Office for Treatment Improvement, part of our National Institute on Drug Abuse, as well as some of the dollars that are among the \$171,000,000 that we have as part of our infant mortality initiative to try and get women who are preg-

nant who are on drugs into drug treatment programs so they will get off of drugs and hopefully then end up with a better outcome. We think that is the best approach now, because everything done after birth is somewhat remedial, trying to repair damage that has been done.

DEATHS OF YOUNG BLACK MALES

Mr. STOKES. I am interested in some findings just released last week by the National Center for Health Statistics. You were quoted in *The Washington Post* in reference to these findings. Basically, the study found that more teenage boys die from gunshots than from all causes combined, and a black male teenager is 11 times more likely to be murdered with a gun than a white counterpart.

In the article, I found one of your statements to be particularly poignant. You said: "During every 100 hours on our streets we lose three times more young men than were killed in 100 hours of ground war in the Persian Gulf. Where are the yellow ribbons of hope and remembrance? Where is the heartfelt commitment to supporting the children of this war?"

What can we do at the Federal, local and family levels to address this tragic occurrence in our country?

Secretary SULLIVAN. There are a variety of strategies that I think are necessary, Mr. Stokes, to address this. As I noted in that speech from which that quote is taken, down at Hampton University last week in a Conference on the Black Family—which was the 13th annual conference held at Hampton—I think that shows the concern about the health of the black family and its welfare is not a new-found concern within the black community. We have had a number of centers that have been concerned about that.

But we have a variety of programs. First of all, I mentioned our minority male initiative, but I emphasized we have a variety of programs whose bottom line, point of commonality, is working to strengthen the family, to provide role models and guidance for our young people, to try and decrease incidents of single-parent families and teenage pregnancy; where we oftentimes have teen mothers who themselves are children having children.

There are a variety of programs in this Department that are all parts of the same mosaic addressing, the same bottom line, working to strengthen the family, providing education as well as instruction, and other services to the family.

I will be happy to share a listing of those programs with you. I should emphasize. That we need to have a greater sense of commitment within our communities to make our neighborhoods safe.

We certainly are all for law enforcement, but we need to have residents in communities themselves seeing they have a responsibility to report crime and do everything they can to make their neighborhoods safe.

Mr. STOKES. I noted that last year, responsibility for keeping this data was transferred from the National Institute of Justice to the Centers for Disease Control. This signals that the homicide rates for African-American males is not so much a criminal issue as it is a national health issue.

Do you see it in that context, that it is a national health issue?

Secretary SULLIVAN. Very definitely. I have stated on a number of occasions that this is a public health issue. By that, I mean we know a number of these homicides can be prevented by a variety of strategies. The basic thrust of those strategies is to teach our young people how to resolve conflicts without resorting to violence.

We also are concerned about the frequent depiction of violence on our television screens, including cartoons that young children watch. They suggest in these television dramas that violence is an accepted way of conflict resolution.

We are funding, a number of projects to address this. One of them in Boston that Dr. Deborah Brostiff with her colleagues has, developed in Boston a curriculum for high school students to teach young people how to resolve conflicts without resort to violence.

Another project in Philadelphia that is under Sister Filoca, who has been able to adopt several teenage gangs, and channel their energies from violence to constructive community work, as well as adopt a reward system for constructive behavior in the community.

We have found similar projects here at Shiloh Baptist Church in D.C., and another in Los Angeles. So, indeed, there are a variety of strategies when coupled with prevention, firm law enforcement, and working with the people in the community, they can be successful.

Mr. STOKES. My time has expired. Thank you very much, Mr. Secretary, and I yield to Mr. Early.

HEALTH OBJECTIVES

Mr. EARLY. Dr. Sullivan, 10 years ago, the Public Health Service said health objectives would be completed by 1990. Have we met those objectives?

Secretary SULLIVAN. There were approximately 200 of those objectives that were established in 1980, for 1990, Mr. Early. The outcome of that is as follows: About half of those objectives indeed were met, such as lowering the incidence of death from strokes and hypertension programs.

But about a quarter of the objectives we clearly did not meet, infant mortality being one of them. The other quarter are objectives where, unfortunately, they were not set up in 1980 in a way we could measure them in 1990.

In establishing our objectives for the year 2000, we learned from that experience, and we have 298 health objectives for the year 2000, which were developed over a three-year period starting in 1987 with our Public Health Service's, our Office of Health Promotion and Disease Prevention, working along with our Assistant Secretary for Health. These 298 health objectives are grouped under 22 priority areas.

They include such things as lowering the incidence of smoking in our population from its present level of around 27 percent of our population to less than 15 percent of our population; lowering our infant mortality rate to less than seven infant deaths per 1,000 births as compared to 10 or 9.8, where it is now.

Mr. EARLY. Aren't those two good examples of government, Dr. Sullivan, a little bit of money on hypertension and a little bit of

money for education on the dangers of smoking? Aren't those two examples of really addressing the problem?

Secretary SULLIVAN. Oh, very definitely, yes.

Mr. EARLY. On the Chairman's question about screening, Dr. Sullivan, minority women having triple the rate of breast cancer as white women, is that because they are minorities or because they are poor?

Secretary SULLIVAN. I think that most of this is related to income status; that is, because they are poor. I think the rate of breast cancer is comparable, but the death rate from breast cancer in minority women is greater than in white women, although the incidence is comparable.

We don't have all the answers; whether it is delayed diagnosis, compounding illness such as perhaps kidney disease or some other factor which makes it higher. We know that we can reduce the death rate from breast cancer by more aggressive mammography screening for blacks and whites, and that is why we are so pleased to have our mammography initiative at the level of funding that is in the budget.

Mr. EARLY. But not to the degree it should be. I think you fudged it a little bit, Doctor. I mean whether it is nutritional, diet, especially in outreach. I think that mammography screening is not available to poor people as much and I hope you are going to expand that screening. I think early detection really helps us to address cancer.

Secretary SULLIVAN. Oh, very definitely. One of the factors, Mr. Early, if I might add, is a parallel situation, about a year ago there was a study from the Harvard School of Public Health looking at the infant mortality rate among black women versus white women matched by socioeconomic status, income, educational level, etcetera.

They still found a greater, not striking, but still statistically significant greater incidence of infant mortality among the minority women.

We don't know why that is. There is speculation, that part of it is because so many of the minority women who are middle class may have grown up poor; that is they may have moved up during their lifetime as opposed to the white women who may have been born middle class, and therefore had a different health experience growing up.

COMMUNITY HEALTH CENTERS

Mr. EARLY. Lets talk about the targeted infant mortality initiative. The administration has proposed funding a new infant mortality initiative aimed at reducing infant mortality rates in ten cities where infant mortality rates are excessively high.

The proposal will be financed—this is my problem—in part by reprogramming funds from community health centers and maternal and child health programs. I can only tell you in my city, in my largest city, Worcester, it is the community health center at Great Brook Valley that plays a key role in reducing infant mortality by educating the poor people.

How can we take the money from those two groups and think we are doing the right thing? Shouldn't that be new money, Doctor?

Secretary SULLIVAN. Well, Mr. Early, as I said before, we would be very pleased to have these dollars by whatever mechanism we could get them. The important thing for me is that we get them. On the specific issue of the reprogramming, what we propose to do is to keep the funding for the community health centers and the maternal and child health programs level funded. That is, we are not going to reduce them, but rather take the increase in those programs and target that increase towards the infant mortality initiative.

Mr. EARLY. My problem with that, Dr. Sullivan, is that in my area the community health center is doing the best in addressing the infant mortality problem.

I think that the infant mortality rate in my area is going to go down because a little woman doctor out at Great Brook Valley Health Center is educating the poor people.

I have trouble taking the money from that program to address a problem. I could see how embarrassed you were, Doctor, when you said the United States ranks 24th in infant mortality.

I mean, the City of Boston is second. I don't understand that. I don't see a big enough commitment to reducing the infant mortality rate. One thing I don't want to do is take funds from community health centers and maternal and child health programs, and I am going to suggest that when it comes up with the Chairman.

Let me again get to the specifics of your budget. Among the ten budget categories receiving the largest reductions relative to the current service base line is medicare. That is under your department isn't it, Doctor?

Secretary SULLIVAN. Yes, it is.

Mr. EARLY. Other income security programs, such as the low income fuel assistance, the refugee program, are under your department to, right, Doctor?

Secretary SULLIVAN. Yes, they are.

Mr. EARLY. Health care services, under you, Doctor?

Secretary SULLIVAN. Yes.

Mr. EARLY. The maternal and child health block grant?

Secretary SULLIVAN. Yes.

Mr. EARLY. ADAMHA block grant, all in your department, Doctor?

Again, your statement is as fine as it can be, but there has got to be some monies for the project. I think this budget for your programs is inadequate, Doctor.

Secretary SULLIVAN. Well—

Mr. EARLY. I know what you are going to tell me. I really am concerned about the specifics of this budget.

APPOINTMENT OF DR. HEALY

Mr. Natcher, I think what Secretary Sullivan told us at the outset was the biggest indictment of the system we could have—taking six months to certify Dr. Healy, it shouldn't have taken six days. I am putting the blame on all of us for that.

I question the need for the FBI had to do that type of investigation. I think that is one of the reasons why it has been vacant for two years, Dr. Sullivan. What are you going to suggest to correct that?

Secretary SULLIVAN. Well, let me say that I have discussed this issue, as have other members of the cabinet who have suffered similar kinds of problems with our personnel procedure, and they are looking at the system to see if we can come forward with better and faster ways of getting through the system.

Mr. EARLY. You can't legislate morality, can you? Why shouldn't you submit a name and let the FBI have 15 or 30 days to find out if there is a problem, and if they don't find anything the name goes in?

This is crazy. It doesn't work. It happened to the Democrats. It happens to the Republicans. No individual, just the system is wrong.

Six months to get Dr. Healy confirmed, Mr. Natcher, is terrible. Do you think you lost any applicants because of the scrutiny that they give these applicants in applying for the job?

Secretary SULLIVAN. Oh, I think there is no question about it. There are a number of people in the scientific community who have indicated that this is a great job, that this is very exciting, but I don't want to put myself and my family through this process because not only does it take so long, but almost invariably things get leaked, before the candidate knows whether or not he or she really is interested; or whether we really want to proceed.

I would welcome any help that we could get to improve the process. I really think in a sense we are shooting ourselves in the foot in that we have an excellent position, a real leadership opportunity, but all of the things that we have to wade through to get there really, in effect, take away from the position.

Mr. EARLY. Mr. Natcher, would it be proper to ask Dr. Sullivan to ask the FBI for the cost of the investigation of Dr. Healy?

Mr. NATCHER. It would be all right.

Mr. EARLY. If you would put that in the record. Given your description of Dr. Healy, it shouldn't have taken six days. In a different area, there are 79 new judges that have to be screened, and we can't have that.

The system isn't going to work. Mr. Chairman, I want to thank you.

[The information follows:]

BACKGROUND INVESTIGATION OF DR. HEALY

In his statement that the background check on Dr. Bernadine Healy for NIH Director took five months, the Secretary was referring to the length of the entire process of White House consideration of the candidate, including the expedited full field investigation (FFI) performed by the FBI. In fact, the actual FFI for Dr. Healy was completed within 26 calendar days from the date that the candidate returned her completed security forms to the White House security office. The FBI does not charge agencies for the costs for its Presidential appointee investigations.

Mr. EARLY. I want to thank you, Dr. Sullivan, as far as justifying an inappropriate budget as well as you did.

Secretary SULLIVAN. Thank you, Mr. Early?

Mr. NATCHER. Mr. Secretary, not only Mr. Early, but I and other members of the subcommittee have talked with you somewhat about the appointment of a new director, but I want you to know on the record that Dr. Raub has certainly performed in an excellent manner as your assistant and as the Acting Director pending the selection.

He has worked with us, and I think he has performed in an excellent manner, Mr. Secretary, and I just want you to know that.

Secretary SULLIVAN. Thank you very much, Mr. Chairman.

Mr. EARLY. I certainly do. I think Dr. Raub was—he was restricted from filling the job, but I agree with the Chairman, he did an outstanding job.

Mr. NATCHER. He certainly has, Mr. Secretary.

VACCINE INJURY CLAIMS

Mr. Secretary, as you know, the Senate reported out a supplemental last week which included \$100,000,000 for pre 1989 vaccine injury claims. We understand that the federal liability for these claims may eventually reach several billion dollars.

What is the Department's position as far as this \$100,000,000 that the Senate added? Have you taken a position on this amount and this procedure that has come from the other side, Mr. Secretary?

Secretary SULLIVAN. Yes, Mr. Natcher, we think this is a beginning. Of course, one of the questions we have is that the authorization level is only for \$80,000,000 for this program. When this legislation was first enacted, we really had no idea what the actual cost of the program would be, or the number of claims for vaccine injury that would be submitted prior to the closing date. One estimate from one of our advisory committees is that the total cost of these claims, if they were all proven to be valid, could be as much as \$2,000,000,000.

We are reviewing these claims, and it is going to take us some time before we have all of that done, but it would appear that we may very well have to come back to the Congress. The magnitude of the problem may be much greater than the funds that have been made available thus far.

Mr. NATCHER. Any questions, Mr. Early?

Mr. EARLY. No, Mr. Chairman. I will supply mine for the record.

Mr. NATCHER. That will be fine. Mr. Secretary, we want to thank you for appearing before our committee at this time in behalf of your budget request for the fiscal year 1992. As I said in the beginning, you have presented us a budget that is a good one to start with.

You are to be commended on presenting to us the highest amount of an increase for the NIH of any Secretary in the history of the Department.

That means a whole lot to Mr. Early and all the members of the subcommittee, and we appreciate it. Mr. Secretary, we want to thank you. This has been a good hearing.

Secretary SULLIVAN. Thank you, Mr. Chairman and Mr. Early.

It is always a pleasure to appear before you. We certainly appreciate your interest and your support for our programs. We look forward to our continuing work with you. Thank you.

Mr. NATCHER. Thank you, sir. The committee will now adjourn until 10 o'clock in the morning.

[The following additional questions were submitted to be answered for the record:]

AIDS

N-1 Mr. Natcher: Did the Department request additional funds for Ryan White activities when you submitted your original 1992 request to the Office of Management and Budget?

Secretary Sullivan: The HHS budget was originally developed prior to the passage of the Ryan White Comprehensive Care Act. Therefore, the Department budget did not include funding specifically for the "Ryan White" activities.

N-2

BREAST CANCER/WOMEN'S HEALTH

Mr. Natcher: Many members of the House are concerned about the Department's attention to breast and cervical cancer. We note that you have requested the full \$50 million authorized for screening programs; can you give us an idea of how your proposed FY 1992 level of effort in all areas, including research compared to 1991?

Secretary Sullivan: As you noted, we have requested a total of \$50 million for the breast and cervical screening program, an increase of \$20.7 million compared to the FY 1991 level of \$29.3 million. We are also seeking \$9.7 million for the National Cancer Institute's (NCI) breast cancer education program, up from \$9.2 million in FY 1991. The FY 1992 request included an estimated \$93 million for NCI's research and related activities concerning breast cancer, an increase of \$12 million over FY 1991. It also includes \$48 million for cervical and related cancers, an increase of \$2 million compared to FY 1991. As you know, we expect HCFA Medicare expenditures for breast and cervical cancer screening to increase 52% from FY 1991 to FY 1992, for an estimated total of \$350 million in FY 1992.

N-2a

Mr. Natcher: Please insert a table showing spending throughout the Department on breast and cervical cancer.

Secretary Sullivan: The table follows:

(Dollars in Millions)		
	<u>FY 1991</u>	<u>FY 1992</u>
PHS:		
CDC Breast and Cervical Screening Program.....	\$29.3	\$50.0
NCI Breast Cancer Screening Ed..	9.2	9.7
NCI Breast Cancer Research and Related Activities.....	81.0	93.0
NCI Cervical and Related Cancers Research and Related Activ.....	<u>45.7</u>	<u>47.7</u>
Subtotal, PHS.....	\$165.2	\$200.4
HCFA:		
Medicare Mammogram.....	\$170.0	\$290.0
Medicare Pap Smears.....	60.0	60.0
Subtotal, HCFA.....	<u>\$230.0</u>	<u>\$350.0</u>
Total, HHS.....	\$395.2	\$550.4

STATE LEGALIZATION IMMIGRATION ASSISTANCE GRANTS

N-3

Mr. Natcher: Your budget assumes what amounts to a \$1,123 million rescission of funds for the Immigration Assistance account based on your conclusion that States will not have valid claims for these funds next year. How dependable is the data which is behind this proposal?

Secretary Sullivan: Our conclusions and budget recommendations for SLIAG for FY 1992 are State data on actual spending patterns and estimates. State costs have been much lower than both the Department and the States expected back in 1986. These earlier estimates of need seem to be excessive. The dependability of State spending data and estimates is supported by two HHS Office of Inspector General reports which conclude that SLIAG funds allotted to States will greatly exceed actual expenditures; that States' projections have consistently overestimated budget needs; and that "a large appropriation could be an incentive to excessive and wasteful expenditures."

N-4

Mr. Natcher: Is it the Department's position that these funds will not be needed in 1992 or that they will not be needed at all?

Secretary Sullivan: The Department, in requesting rescission of \$1.1 billion in FY 1992, recognizes that by FY 1992 most of the objectives which Congress set for legalization will have been met. Most of the direct impacts of legalization - public health costs and education services to allow these aliens to remain in this country - have already been met with only part of the funds which States have already received. For instance, over 90 percent of all "pre-82" legalized aliens and Special Agricultural Workers, or SAWs, who have been granted temporary resident status have now adjusted to permanent resident status. The remainder of funds still available are ample to carry out Congress' intent to mitigate some of the fiscal impact on State and local governments of the Federal decision to grant legal status to previously illegalized aliens. Many of the costs States are claiming now would have been incurred even if IRCA had never been enacted. These impacts appear to be less than Congress anticipated when it established the funding level for SLIAG in 1986.

INFANT MORTALITY INITIATIVE

N-5

Mr. Natcher: Dr. Sullivan, you propose to spend \$171 million on the "Healthy Start" infant mortality initiative in 1992, which seems like a lot of money for ten grantees. Tell us more about how you plan to use this funding and why you believe \$171 million is an appropriate program level.

Secretary Sullivan: We need \$57 million in FY 1991 and \$171 million in FY 1992 to begin to tackle the problem of infant mortality in our communities which are hardest hit. We have already spend billions of dollars on the problem and have improved survival rates for many, but for minorities and other high risk populations we still have a substantial problem. The Healthy Start Program will be more than business as usual, because business as usual is not enough.

We are asking communities to band together to reduce their extremely high infant mortality rates for their hardest to reach populations by 50 percent over 5 years. That takes money. With these funds communities are expected to integrate existing primary care and social services for pregnant women and their infants; provide services currently needed but not available; aggressively seek out these women in need of prenatal care and bring them into care; and collect data and evaluate their progress so we can learn from these projects and apply what we learn to other areas with high infant mortality rates.

Examples of services included would be outreach, home visits, case management, parenting information, drug and alcohol prevention and treatment and smoking cessation, transportation, child care, and job training.

N-6

Mr. Natcher: A matter of concern to our chairman, Mr. Whitten, and other members of the Committee is that this initiative seems focused on cities, even though we know that some rural areas have extremely high infant mortality rates. Can you assure us that rural areas with high infant mortality rates will be eligible to apply?

Secretary Sullivan: Rural areas will be eligible to become Healthy Start grantees.

LOW INCOME HOME ENERGY ASSISTANCE PROGRAM

N-7

Mr. Natcher: Press reports last December indicated that the Department was proposing to greatly reduce the Low Income Home Energy Assistance Program and limit it to geographic areas with unusual needs. In general, do you favor changing Federal energy assistance to an emergency program for unanticipated needs rather than a regular income supplement?

Secretary Sullivan: We are faced with making difficult budgetary decisions, and with regard to LIHEAP we believe that the Federal government should provide benefits only in circumstances of exceptional need. Many options were considered for the LIHEAP program, which was created in the early 1980's as a measure to supplement other sources of energy assistance.

The proposal referred to was based upon the fact that the Northeast region is most dependent upon home heating oil, which is subject to a volatile international market and therefore its price

has been less stable than the prices of natural gas and electricity. Nationwide only 12% of the population use heating oil, but in the Northeast 40% of the population (and 44% of the low-income population) rely on heating oil as the primary source of energy. Low-income residents of Northeast States are more than five times more likely to use fuel oil as their main source of heating fuel (43.8%) than are low-income residents of the North Central (8.1%), South (4.7%), and West (0.5%) States. Even when liquefied petroleum gas and kerosene are included as fuel oil, low-income residents of the Northeast are more than twice as likely to use fuel oil as the main source of heating fuel.

This proposal was but one option that we considered regarding the LIHEAP program, but it was not the preferred option that is included in the President's budget.

Energy assistance programs were created in the early 1970's as one of the Federal responses to the sharp increases in energy prices and the consequent immediate effect on low income households. LIHEAP, created in the early 1980's, was established to supplement other sources of assistance, not to supplant them. Many other Federal, State, and private sources supply funds for energy needs. With the overall budgetary limitations, we have had to make many priority determinations, and it is our best judgement that special energy assistance should be focused toward emergency crisis situations, and should be funded at a level of \$1.025 billion, approximately 37% less than in FY 1991.

N-8

Mr. Natcher: Can you tell us in more detail what impact you believe your 1992 request will have on people who traditionally have been served by the Low Income Home Energy Program?

Secretary Sullivan: LIHEAP is a block grant program that gives States the flexibility to operate their own programs to best serve the needs of its citizens. In response to reductions in funding levels, the States can reduce the number of households served, cut back on the amount transferred to other block grants, reduce administrative costs or carryover, add State oil overcharge funds to LIHEAP, or leverage funds in the private sector. With all these options, we are unable to determine what the exact impact will be in any one State or in the nation as a whole. However, the fact that many States continue to transfer the legal maximum of LIHEAP funds to other block grants (28 States transferred \$52 million in 1990) suggests that a reduction is warranted. In addition, The President's Budget takes into account the fact that the home energy burdens as a percent of household income for low-income households has declined between FY 1981 and 1989, from 8.0 percent to 5.4 percent, indicating a reduced need for LIHEAP in offsetting home energy costs as a percent of household income.

In addition, the inclusion of a \$100 million LIHEAP contingency fund in FY 1992 allows the Federal government to play its appropriate role with regard to energy assistance, that is, providing benefits only in circumstances of exceptional need.

N9

Mr. Natcher. Your 1991 budget requested about 1,900 additional FTE. When all was said and done, you used the 1991 appropriation to provide about 4,100 new FTE. Now, for 1992, you are requesting another 2,900 staff. Should we be at all concerned about this rapid staff buildup?

Secretary Sullivan. The 1991 President's Budget estimated that the Department would utilize 119,606 full-time equivalents (FTE) in carrying out its programs at the levels allowed for in that budget. The appropriation, as passed, provides for increased levels of funding and higher levels of service for a number of programs throughout the Department. These increases are of a magnitude which exceeds the capability of the workforce originally projected. In order to adequately meet these expectations, a greater number of workyears will be required in FY 1991 than originally estimated, and this trend will continue into FY 1992 as workloads and the associated funding increase.

N10

Mr. Natcher. Dr. Sullivan, we would appreciate it if your staff would provide for the record a table showing the Department's 1992 staffing request by agency and the current 1991 staffing estimate, as well as an explanation of the major changes.

1990 actual FTE: 117,718

1991 FTE request: 119,606

1991 actual FTE: 121,841

1992 FTE request: 124,745

Secretary Sullivan. The following table provides the breakdown of full-time equivalents originally estimated for use in FY 1991 based on the President's Budget and based on the current appropriation. The major differences in these two estimates are in the Indian Health Service, Health Resources and Services Administration, and Agency for Health Care Policy and Research. The Indian Health Service accounts for almost 50% of the Departmental change with its increase of 1,097. The Health Resources and Services Administration received a higher level of dollars in its appropriation for Health Professions and Family Planning which accounted for the majority of the 260 FTE increase in that account. The increase of 58 FTE in the Agency for Health Care Policy and Research occurred as a direct result of the increase in funding provided by the 1991 appropriation.

**DEPARTMENT OF HEALTH AND HUMAN SERVICE
SUMMARY OF FTE FY 1991**

	FY 1991 PRESIDENT'S BUDGET	FY 1991 CURRENT ESTIMATE
PUBLIC HEALTH SERVICE:		
Food and Drug Administration.....	8,444	8,444
Health Resources & Services Admin.....	1,956	2,216
Indian Health Service.....	12,751	13,848
Centers for Disease Control.....	5,132	5,272
National Institutes of Health.....	14,133	14,269
Alcohol, Drug Abuse, & Mental Hlth.....	2,048	2,071
Health Care Policy Research.....	178	236
Office of Asst. Secretary/Health.....	819	823
Subtotal, Public Health Service.....	45,461	47,179
HEALTH CARE FINANCING ADMIN.....	4,127	4,127
SOCIAL SECURITY ADMINISTRATION:		
Black Lung.....	146	146
Reimbursable.....	578	578
Limitation on Admin. Expenses.....	62,875	62,972
Zebley.....	--	300
Subtotal, Social Security Admin.....	63,599	63,996
FAMILY SUPPORT ADMINISTRATION.....	1,029	1,052
OFFICE OF HUMAN DEVELOPMENT SVCS.....	1,000	1,002
OFFICE OF THE SECRETARY:		
General Departmental Management/WCF.....	2,623	2,691
Office of the Inspector General.....	1,415	1,437
Office for Civil Rights.....	325	325
Policy Research.....	5	10
Subtotal, Office of Secretary.....	4,368	4,463
OFFICE OF CONSUMER AFFAIRS.....	22	22
TOTAL, HEALTH & HUMAN SERVICES.....	119,606	121,841

DRUG ABUSE TREATMENT

N-11

Mr. Natcher: We have targeted almost \$5 billion to drug treatment programs in the last five years, mostly through block grants. You are proposing to spend another \$1.4 billion on treatment activities in FY 1992. Is drug treatment absorbing resources that could be used more productively elsewhere in your Department, such as for primary care and prevention?

Secretary Sullivan: While we have made great progress in the War on Drugs, we can not claim victory yet. I believe that the \$1.8 billion requested in my FY 1992 HHS budget for anti-drug abuse activities is crucial to a healthy and strong Nation. This level of support includes \$990 million for treatment services, \$467 million for prevention and \$367 million for research. As identified in the President's third National Drug Control Strategy, more people need treatment in this country than the treatment system capacity can provide.

N-12

Mr. Natcher: Many people have called for a drug budget which provides for treatment on demand. Given the difficulty in finding locations for drug treatment and the modest success rates of many of the programs, could the drug treatment system productively use additional dollars in 1992?

Secretary Sullivan: While recent data such as the High School Senior Survey and the National Household Survey show that we are making progress in the War on Drugs, we still need more treatment services than are currently available. I do agree that it is important to ensure that additional treatment dollars go to those areas most in need. That is why my budget proposes a new \$99 million treatment program that will provide grants to States based on community needs assessment and the State's plan for providing drug treatment services. Expanding drug treatment capacity through this mechanism is preferable to the Alcohol, Drug Abuse and Mental Health Services Block Grant because it allows us to target our resources to communities which need them the most.

DELAYED OBLIGATION OF FUNDS

N-13. Mr. Natcher: Identify by account the 1992 outlay savings associated with the proposed delayed obligation of funds.

Secretary Sullivan: The total amount of deferred obligations of funds in 1992 is \$1,392 million. The accounts with deferred obligations are as follows:

Agency	Deferred	Savings
(dollars in millions)		
PHS:		
HRSA.....	\$86	\$51
CDC.....	94	52
NIH.....	400	168
SSA (LAE).....	80	80
FSA:		
Child Care...	\$732	271

N-14

PEDIATRIC AIDS

Mr. Natcher: Please provide a table identifying HHS resources targeted to Pediatric AIDS for FY 1990 - FY 1992.

TBL

Secretary Sullivan: The table you requested follows showing discretionary expenses related to Pediatric AIDS for FY 1992:

(Dollars in Millions)

	<u>FY 90</u>	<u>FY 91</u>	<u>FY 92</u>
HRSA.....	\$14,803	\$19,518	\$19,518
CDC.....	27,709	42,237	42,237
NIH.....	7,481	93,082	111,778
ADAMHA.....	12,414	13,960	15,215
AHCPR.....	263	1,011	955
Total, PHS.....	\$132,670	\$169,808	\$189,703

TBL

N-15

MINORITY TRAINING PROGRAMS

Mr. Natcher: Provide a table displaying funding for minority training programs throughout the Department for 1990-1992.

Mr. Sullivan: The following table reflects HHS minority training program funding for 1990 through 1992.

MINORITY HEALTH AND TRAINING (NIH, HRSA, ADAMHA)

(Dollars In Millions) a/

	<u>FY 1990</u>	<u>FY 1991</u>	<u>FY 1992</u>
	<u>Enacted</u>	<u>Enacted</u>	<u>Pres. Budget</u>
HRSA:			
Health Professions Training.....b/.....	\$45.5	\$55.7	\$59.9
Hispanic Centers.....	---	1.5	1.5
Native American Centers.....	---	1.0	1.0
Community Health Professions Scholarships.....	---	0.5	0.5
Health Professions Student Loans Recapitalization.....	---	2.9	15.0
Data Collection (NCHS/CDC transfer).....	---	1.0	1.0
National Health Service Corps Scholarships & Loans.....	8.9	8.9	8.9
Special NHSC Scholarship Initiative.....c/.....	---	39.9	44.9
Grants for Scholarships.....	---	8.3	8.3
Faculty Services.....	---	1.0	1.0
Native Hawaiian Health Care/Scholarships.....	3.3	5.9	---
Services In/Near Public Housing Projects.....	---	3.4	3.0
Subtotal, HRSA.....	\$57.6	\$129.9	\$144.9
NIH:			
Minority Biomedical Research Support.....	\$39.8	\$42.9	\$45.2
Minority Access to Research Careers.....	10.7	14.1	15.6
Research Centers at Minority Institutions.....	18.8	24.1	25.4
Minority High School Student Apprenticeship Office.....	2.1	8.3	8.9
Sickle Cell Research.....	33.4	36.9	37.3
AIDS Research.....	52.4	89.1	97.8
Office of Minority Health.....	---	2.5	2.5
Extramural Construction at Minority Institutions.....	---	---	15.0
Subtotal, NIH.....d/.....	\$157.1	\$217.8	\$247.8
ADAMHA:			
Minority Access to Research Careers.....	\$1.4	\$1.6	\$1.7
Research Supplement for Underrepresented Minorities.....	1.7	2.0	2.1
Minority Biomedical Research Support.....	0.8	0.3	0.2
Minority Maternal Health.....	0.6	0.9	0.9
Minority High School Apprenticeship Program.....	0.2	0.3	0.4
Minority Fellowship Program.....	3.2	3.3	2.3
Minority Institutions Research Development Program.....	2.2	3.4	3.6
Minority Research Scholarship Program.....	0.4	0.4	0.4
Subtotal, ADAMHA.....d/.....	\$10.5	\$12.1	\$11.5
TOTAL, HRSA, NIH, & ADAMHA Minority Spending.....	\$225.2	\$359.8	\$404.2

Notes:

a/ Figures may not add due to rounding.

b/ Minority Disadvantaged Assistance, Nurse Disadvantaged Assistance, Exceptional Need Scholarships and Excellence In Minority Health Education Grants.

c/ Part of Secretary's Minority Health Initiative; may not be 100% minority.

d/ Does not include individual grant projects specifically directed to the study of minority populations.

tbl
N-16

GENERAL PROVISIONS

Mr. Natcher: Provide an explanation of each change being proposed in the Title II or Title V General Provisions related to HHS programs.

Secretary Sullivan: The follows table provides the explanation requested.

Title II

Sec. 202. The Federal Employees Pay Comparability Act of 1990 established a senior level positions pay band in lieu of "supergrades" GS 16, 17, and 18 which were abolished. The language of this provision is revised in accordance with the new law.

Sec. 209. This provision is proposed for deletion, as it limits the Department's flexibility to allocate personnel resources.

Sec. 211. This provision, which prohibits using Federal funds appropriated under this Act for any project which involves the capture or procurement of chimpanzees obtained from the wild, is proposed for deletion. The language duplicates existing regulation and provisions within the CITES (Convention on International Trade of Endangered Species) Treaty.

Sec. 211. The adoption of this provision would simplify payments of user fees by States to the Family Support Administration (FSA) for services provided by the Office of Child Support Enforcement. Currently, FSA grants Child Support Enforcement matching funds to States. States who use technical services offered by FSA (preparing and mailing tax offset notices) then send funds back to FSA's salaries and expenses account. This provision simplifies bookkeeping by allowing FSA to deduct from grants the costs of technical services States have requested, and to transfer the funds to the salaries and expenses account.

Sec. 213. This provision is revised to allow for the full effect of the January 1991 4.1 percent pay raise.

Sec. 214. This provision, which duplicates a provision in substantive law and existing administrative guidelines on AIDS education programs, is proposed for deletion.

Title V

Sec. 512. This provision, a one-time provision relating to absorption of the 1991 pay raise, is proposed for deletion.

Sec. 513. This one-time provision, which limits distribution of sterile needles, is proposed for deletion.

Sec. 514. This provision, a one-time reduction in salaries and expenses, is proposed for deletion.

Sec. 515. This provision, a one-time provision for transfers in FY 1991, is proposed for deletion.

ABORTION

N-17

Mr. Natcher: Identify the number of Federally financed abortions each year from 1978 to the present.

Secretary Sullivan: Since 1978 the Department has, as a result of the Hyde Amendment, systematically reported information on Medicaid financed abortions and allowable abortion-related expenditures. Since February 14, 1978, Medicaid financed abortions total 60,121. The table below represents the number of abortions by fiscal year:

<u>FY1978</u>	<u>FY1979</u>	<u>FY1980</u>	<u>FY1981</u>
1,335	3,675	33,625	17,495
<u>FY1982</u>	<u>FY1983</u>	<u>FY1984</u>	<u>FY1985</u>
783	856	893	865
<u>FY1986</u>	<u>FY1987</u>	<u>FY1988</u>	<u>FY1989</u>
232	91	135	67
<u>FY1990</u>			
69			

SUDDEN INFANT DEATH SYNDROME

Mr. Natcher: Provide a table identifying spending on Sudden Infant Death Syndrome throughout the Department for 1990-1992.

Secretary Sullivan: The table follows.

	<u>FY 1990</u>	<u>FY 1991</u>	<u>FY 1992</u>
National Institute of Child Health and Human Development.	\$36.4	\$38.5	\$41.5
National Institute of Neurological Disorders and Stroke	3.0	2.5	2.6
National Center for Research Resources.	0.1	0.2	0.2
Subtotal, NIH	\$39.5	\$41.2	\$44.3
Health Resources and Services Administration	0.4	0.5	0.3
Total, HHS.	\$39.9	\$41.7	\$44.6

UNAUTHORIZED PROGRAMS

Mr. Natcher: Provide a list of all programs funded in 1991 or proposed in 1992 which are not presently authorized for 1992.

Secretary Sullivan: The list of programs that are funded in 1991 or proposed for funding in 1992 that are not presently authorized can be found below.

	<u>Expired Legislation</u> FY 1991	FY 1992
<u>Public Health Service</u>		
HRSA:		
Health Professions:		
Exceptional Financial Need		
Scholarships.....	\$9,759	\$10,400
Disadvantaged Assistance.....	30,817	32,841
Nurse Education Opportunities...	3,416	4,160
Family Planning.....	<u>144,311</u>	<u>150,000</u>
Subtotal, HRSA.....	\$188,303	\$197,401
CDC:		
Preventive Health Services:		
Block Grants, PHSA Title XIX....	\$90,845	\$101,503
Prevention Centers		
PHSA Sec. 1706(e).....	4,367	3,949
Sexually Transmitted Diseases		
Grants, PHSA Sec. 318(d)(1)...	73,638	73,638
Chronic & Environmental Disease		
Prevention, PHSA Sec. 317A....	<u>7,790</u>	<u>8,949</u>
Subtotal, CDC.....	\$168,850	\$179,090
NIH:		
National Library of Medicine:		
Medical Library Assistance.....	\$14,691	\$16,309
Biotechnology Information.....	<u>10,466</u>	<u>10,937</u>
Subtotal, NIH.....	\$25,157	\$27,246
ADAMHA:		
General Mental Health:		
Instrumentation Grants.....	\$1,328	\$1,338
Drug Abuse:		
Instrumentation Grants.....	504	524
Demonstrations.....	118,658	118,505
Alcohol: Instrumentation Grants...	575	581
Substance Abuse Prevention:		
Demonstrations.....	211,121	239,357
Clinical Training.....	25,986	25,986
Program Management & Training....	14,200	16,237
Treatment:		
Treatment Improvement Programs,		
PHSA Sec. 509(G) & 517.....	153,204	212,246
Grants to States.....	<u>1,268,670</u>	<u>1,268,670</u>
Subtotal, ADAMHA.....	\$1,794,246	\$1,883,444

OASH:

Population Affairs:

Adolescent Family Life.....	\$7,789	\$12,000
Disease Prevention & Health Promotion.....	<u>4,577</u>	<u>4,577</u>
Subtotal, OASH.....	<u>\$12,366</u>	<u>\$16,577</u>

TOTAL, PHS.....	\$2,188,922	\$2,303,758
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Family Support Administration

Energy Emergency Contingency Fund..	\$195,180	\$100,000
Office of Refugee Resettlement.....	<u>410,630</u>	<u>410,630</u>
TOTAL, FSA.....	\$605,810	\$510,630

Office of Human Development Services

Child Abuse.....	\$39,523	\$39,523
Temporary Child Care & Crisis Nurseries.....	11,055	11,055
Adoption Opportunities.....	12,687	12,687
Youth Gang Drug Prevention.....	14,786	14,786
Runaway Youth Drug Prevention.....	14,786	14,786
Abandoned Infants Assistance.....	12,557	12,557
Family Violence Prevention & Services.....	10,735	10,735
Programs for the Elderly.....	792,510	792,510
Programs for Native Americans.....	<u>33,376</u>	<u>33,376</u>
TOTAL, HDS.....	<u>\$942,015</u>	<u>\$942,015</u>

TOTAL, EXPIRED LEGISLATION.....	\$3,736,747	\$3,756,403
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New Authorizations PendingPublic Health Service

ADAMHA:

Consolidated Homeless Program.....	<u>--</u>	<u>\$20,000</u>
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TOTAL PROGRAMS REQUIRING

AUTHORIZATION OR REAUTHORIZATION....	\$3,736,747	\$3,776,403
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S&E Reduction

20

Mr. Natcher. The Committee is concerned that, in allocating the \$50 million salaries and expenses reduction contained in the FY 1992 appropriation, reductions appear to have been taken in line items that are not normally considered to fund Federal salaries and expenses. What criteria did the Department use to determine which line items were appropriate to reduce?

Secretary Sullivan. Section 514 of H.R. 5257 (FY 1992 Labor, Health and Human Services, Education and Related Agencies Appropriations Bill) directed that salaries and expenses be reduced by \$50 million and that an additional \$57 million be taken from the Social Security Administration's Limitation on Administrative Expenses account.

For the \$50 million reduction, the Department applied a proportional reduction of \$25 million based on each Operating Division's (OPDIV) share of the FY 1991 Conference Action for salaries and expenses; and a proportional reduction of the remaining \$25 million based on the FY 1991 Conference Action increases over the fiscal year 1991 President's Budget request for salaries and expenses.

Once the allocation by OPDIV was made, it was left to the discretion of the OPDIV head for line item distribution, within the commonly accepted salaries and expenses categories.

ABSORPTION POLICY FOR PAY RAISE COSTS

N-21. Mr. Natcher: What is the absorption policy that is built into the 1992 budget request for the 1991 and 1992 pay raise costs?

Secretary Sullivan: The absorption policy for increased pay costs provides restoration of the 1991 pay raise absorbed in fiscal year 1991 and 50 percent absorption of the fiscal year 1992 pay raise.

DEPARTMENTAL STAFFING LEVELS

N22

Mr. Natcher. Provide a table showing Department staffing levels by agency for 1983 - 1992. Include a column which compares 1992 to 1991.

Secretary Sullivan. The requested table follows.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

	ACTUAL FTE USAGE										PRES. BUDGET		
	FY 1983	FY 1984	FY 1985	FY 1986	FY 1987	FY 1988	FY 1989	FY 1990	FY 1991	FY 1992	CHANGE		
PHS:													
FDA.....	7,293	7,257	7,190	7,001	6,961	7,210	7,398	7,815	8,444	8,917	473		
HRSA.....	4,738	4,008	3,414	2,948	2,399	2,250	2,181	2,216	2,216	2,064	-152		
IHS.....	10,309	11,035	11,554	11,538	11,616	11,878	12,359	12,713	13,848	14,425	577		
CDC.....	3,996	4,198	4,161	4,150	4,504	4,416	4,710	4,980	5,272	5,417	145		
NIH.....	13,415	13,662	13,108	12,547	12,725	13,250	13,204	13,507	14,269	14,632	363		
ADAMHA.....	1,660	1,643	1,556	1,489	1,577	1,700	1,743	1,889	2,071	2,103	32		
St. Elizabeths	[3859]	[1757]	--	--	--	--	--	--	--	--	--		
AHCPR.....	--	--	--	--	--	--	--	158	236	236	0		
OASH.....	1,600	1,547	1,430	1,422	870	873	946	800	823	829	6		
Total, PHS...	43,011	43,350	42,413	41,095	40,652	41,577	42,541	44,078	47,179	48,623	1,444		
HCFA.....	4,125	4,090	4,020	3,904	3,829	3,812	3,926	3,962	4,127	4,133	6		
SSA.....	82,434	79,841	77,928	75,513	70,988	67,074	64,706	63,361	63,996	65,253	1,257		
FSA.....	1,354	1,236	1,232	1,146	1,046	979	993	996	1,052	1,069	17		
OHDS.....	1,313	1,268	1,166	1,080	1,014	1,001	969	979	1,002	1,090	88		
OS													
GDM.....	3,685	3,223	2,742	2,733	2,656	2,579	2,629	2,582	2,691	2,700	9		
OIG.....	1,408	1,360	1,307	1,225	1,218	1,240	1,331	1,411	1,437	1,510	73		
OCR.....	477	437	397	377	368	344	326	322	325	325	0		
PR.....	15	16	6	5	5	5	5	5	10	10	0		
Clearinghouse.	--	--	--	--	--	--	--	--	--	10	10		
Total, OS....	5,585	5,036	4,452	4,340	4,247	4,168	4,291	4,320	4,463	4,555	92		
Total, HHS.....	137,822	134,821	131,211	127,078	121,776	118,611	117,426	117,696	121,819	124,723	2,904		
OCA.....	34	31	32	29	20	20	19	22	22	22	0		
St. Elizabeths....	3,859	1,757	--	--	--	--	--	--	--	--	--		
Grand, Total....	141,715	136,609	131,243	127,107	121,796	118,631	117,445	117,718	121,841	124,745	2,904		

N-23

EXPENDITURES FOR CHILDREN

Mr. Natcher: Your statement indicates that the Department's child care, child development and child welfare expenditures will total about \$6 billion in 1992. Provide a table which displays funding for these programs for 1989 - 1992 (exclude Indian Health Service).

table

Secretary Sullivan: The following table shows the information you requested.

CHILD CARE AND CHILD WELFARE PROGRAMS -- BUDGET SUMMARY TABLE

PROGRAM	(Budget Authority in \$ millions)				Change
	FY 1989	FY 1990	FY 1991	FY 1992	91-92
<u>Child Care and Development Programs:</u>					
<u>OHDS:</u>					
Head Start.....	\$1,235	\$1,552	\$1,952	\$2,052	\$100
Comprehensive Child Dev.Ctrs.....	20	25	24	24	--
Other OHDS Programs 1/.....	18	23	26	26	--
<u>FSA:</u>					
Child Care and Dev. Block Grant.....	--	--	732	732	--
At-Risk Non-IV-A Child Care.....	--	--	150	300	150
JOBS Child Care.....	17	111	254	350	96
Transitional Child Care.....	--	11	63	83	20
Child Care Licensing Grants.....	--	13	13	13	--
Subtotal, Child Care and Development...	\$1,290	\$1,735	\$3,214	\$3,580	\$366
<u>Child Welfare Programs:</u>					
Foster Care and Independent Living.....	927	1,250	1,873	2,047	174
Adoption Assistance.....	112	125	173	202	29
Child Welfare Services.....	247	253	274	364	90
Other Child Welfare Programs 2/.....	16	28	37	37	--
Runaway and Youth Drug Programs 3/.....	57	68	75	75	--
Child Abuse Programs 4/.....	30	30	59	59	--
Subtotal, Child Welfare.....	\$1,389	\$1,754	\$2,491	\$2,784	\$293
TOTAL.....	\$2,679	\$3,489	\$5,704	\$6,364	\$660

FOOTNOTES FOR BUDGET SUMMARY TABLE

1/ Includes Dependent Care Development Grants, Temporary Child Care and Crisis Nurseries, and Child Development Scholarships.

2/ Includes Adoption Opportunities, Abandoned Infants Assistance, Child Welfare Research, and Child Welfare Training.

3/ Includes Runaway and Homeless Youth, Homeless Youth Transitional Living, Runaway Youth Drug Activities, and Drug Prevention for Youth Gangs.

4/ Includes new Emergency Child Protective Services program, Child Abuse State Grants, Child Abuse Discretionary grants, and Child Abuse Challenge Grants.

HEAD START

OB1

Mr. Obey: I understand that Region V has not yet received direction from your office for awarding 1991 Head Start expansion funds. Where are you in the process of awarding 1991 Head Start expansion funds in federal Region V and why hasn't this necessary direction been given yet?

Secretary Sullivan: A Program Instruction was mailed to all grantees, including those in Region V, on March 19 explaining how the FY 1991 increase will be implemented. The grantees' requests for quality improvement funds are due on May 3, and the expansion requests are due on June 3. The increase for Parent Child Centers will be awarded through a competitive process this summer as will be the funds for Head Start transition grants. The increase for training and technical assistance grants are being awarded throughout the year.

OB-2

Mr. Obey: The Administration has proposed to increase Head Start enrollment by 29,500 with a budget increase of \$100 million. I have some concerns about this proposal. The first is that it directs nearly all the new money for expansion, and second, it appears that the Department is planning to ignore the impact of inflation on current services as well as the Quality Reserve provisions in the Head Start authorization.

What funding level would be required to increase enrollment by 29,500 and meet the requirements for inflation and quality reserve?

Secretary Sullivan: Our budget assumes compliance with both requirements for maintaining service levels. FY 1992 funds will be available for grantees to maintain the current levels of service in their programs. The recent amendments to the Head Start Act do not mandate an automatic cost-of-living increase for all Head Start programs. Instead, it requires that the Secretary not increase enrollment without first assuring that grantees have sufficient funds to maintain FY 1991 service levels. This will be accomplished by allowing grantees to use funds from their FY 1992 increase to maintain services, before they add new children to their programs. Such decisions will be made on a case-by-case basis, since the amount of funds that will be needed to maintain service levels will vary depending on each program's particular circumstances.

As to the quality reserves, there would be no requirement for quality reserves at the President's Budget level. In order to trigger quality reserves, the FY 1992 funding level must exceed the FY 1991 level adjusted for inflation. Given the need to request a more modest increase for Head Start in FY 1992 in order to properly manage the President's enrollment expansion initiative, funding quality set-asides would not be required.

OB-3

Mr. Obey: What percentage of all eligible children (not just four year olds) would be able to enroll in the program with this funding level?

Secretary Sullivan: At the FY 1992 President's Budget level, we will be able to serve 59% of all eligible children for at least one year before they enter school.

OB-4

Mr. Obey: Is it correct that the total cost-of-living increase awarded by your office to local grantees in the last five years has actually been less than half the increase in the consumer price index? How will you rectify the problems this is causing in my Congressional district, where for example, the local Head Start operator in Stevens Point has had to lay off staff and reduce services in order to give its employees cost of living raises?

Secretary Sullivan: Over the past five years, from 1986 to 1991, Head Start funding per child has actually increased at an annual rate of 6.8%, exceeding increases in the consumer price index. In addition to these increases, we will be ensuring that grantees have sufficient funds to maintain service levels by allowing grantees to use funds from their FY 1992 increase to maintain services, before they add new children to their programs. Such decisions will be made on a case-by-case basis, since the amount of funds that will be needed to maintain service levels will vary depending on each program's particular circumstances.

OB-5

Mr. Obey: Health and Human Services has publicly acknowledged that Head Start employees are paid significantly less than their public school counterparts. At the same time, parent involvement is key to the success of the program in terms of children retaining any long term benefits from their participation. How can you justify not providing any program improvement funds this year when programs in my district cannot even afford to keep parent aides on staff?

Secretary Sullivan: It is important to note that in FY 1991, \$195 million was made available of program improvements, allowing for an 11.5% increase per grantee on average. Half of these funds, or almost \$98 million, went directly to increase staff salaries and benefits. This increase is in addition to the \$49 million allocated in FY 1990 for salary increases.

We have been providing these increases at the same time we have been expanding Head Start opportunities to disadvantaged children at an unprecedented pace. Under President Bush's initiative, funding for Head Start has increased 66% since FY 1989, while the number of children served has grown over 40%. Given this rapid growth, we have requested a \$100 million increase for FY 1992 to assure consolidation and improvement of the gains achieved over the past two years by properly managing the large infusions of funding for the program in FYs 1990 and 1991. Given

a level of growth less than inflation over FY 1991, the Head Start amendments recently enacted by the Congress do not envision funding program improvements under such a scenario.

OB-6

Mr. Obey: Transportation for Head Start children is extremely important in rural areas like those found in my district. Bus routes of one and a half to two hours are not uncommon. How can HHS continue to ignore these special problems by awarding cost-of-living increases which are less than the consumer price index and by proposing to discontinue awarding needed program improvement funds?

Secretary Sullivan: Over the past five years, from 1986 to 1991, Head Start funding per child has actually increased at an annual rate of 6.8%, exceeding increases in the consumer price index. In addition to these increases, we will be ensuring that grantees have sufficient funds to maintain service levels by allowing grantees to use funds from their FY 1992 increase to maintain services, before they add new children to their programs. Such decisions will be made on a case-by-case basis, since the amount of funds that will be needed to maintain service levels will vary depending on each program's particular circumstances.

It is important to note that in FY 1991, \$195 million was made available of program improvements, allowing for an 11.5% increase per grantee on average. Transportation improvements are specifically allowed to be funded with these funds.

We have been providing these increases at the same time we have been expanding Head Start opportunities to disadvantaged children at an unprecedented pace. Under President Bush's initiative, funding for Head Start has increased 66% since FY 1989, while the number of children served has grown over 40%. Given this rapid growth, we have requested a \$100 million increase for FY 1992 to assure consolidation and improvement of the gains achieved over the past two years by properly managing the large infusions of funding for the program in FYs 1990 and 1991. Given a level of growth less than inflation over FY 1991, the Head Start amendments recently enacted by the Congress do not envision funding program improvements under such a scenario.

LOW INCOME HOME ENERGY ASSISTANCE

OB-7

Mr. Obey: In Wisconsin, almost 40% of the people receiving assistance from LIHEAP had incomes below 75% of the poverty level and 61.1% had incomes under 100% of the poverty level and 83.8% had incomes under 125% of the poverty guidelines. Do you really believe that these people do not need fuel assistance and that they deserve a 35% cut in benefits, as your proposed budget would do?

Secretary Sullivan: Energy assistance programs were created in the early 1970's as one of the Federal responses to the sharp increases in energy prices and the consequent immediate effect on

low income households. LIHEAP, created in the early 1980's, was established to supplement other sources of assistance, not to supplant them. Many other Federal, State, and private sources supply funds for energy needs. With the overall budgetary limitations, we have had to make many priority determinations, and it is our best judgement that special energy assistance should be funded at a level of \$1.025 billion, approximately 37% less than in FY 1991. The fact that many States continue to transfer the legal maximum of LIHEAP funds to other block grants (28 States transferred \$52 million in 1990) suggests that a reduction is warranted. In addition, The President's Budget takes into account the fact that the home energy burdens as a percent of household income for low-income households has declined between FY 1981 and 1989, from 8.0 percent to 5.4 percent, indicating a reduced need for LIHEAP in offsetting home energy costs as a percent of household income.

OB-8

Mr. Obey: What has your office done to implement the changes in fiscal year 1991 to offer non-traditional LIHEAP intake sites? I have received several reports from my district that working poor people feel uncomfortable going to welfare offices to apply for LIHEAP, especially in small, rural counties where the welfare office is located in the county courthouse. What specifically have you done to offer people alternative sites where they may comfortably apply for these services?

Secretary Sullivan: The recent amendments to the Low-Income Home Energy Assistance Act require that crisis and home heating and cooling assistance be made available at alternative sites such as community action agencies, area agencies on aging, and not-for-profit neighborhood based organizations, beginning in FY 1992. We fully intend to implement this provision for alternative sites for LIHEAP. We expect to issue regulations in the next few months.

OB-9

LEAD POISONING

Mr. Obey: Given the high priority your Department has placed on lead exposure and children, I believe it is important that we do not forget the exposure to the workers who will be doing the lead abatement. In addition to the risk posed to the lead abatement workers, I am concerned about the effects of the secondary exposure to their children. I strongly believe that OSHA should be involved on the lead abatement task force since it would be the lead abatement workers who could inadvertently expose their own children to dangerous lead levels. I understand that you have set up a working group with EPA and HUD, and I was disappointed that OSHA was left off the task force. Please explain this omission.

Secretary Sullivan: The task force you are referring to was established by HUD. I agree that it is important to consider the occupational aspects of lead abatement as well as secondary effects of occupational aspects which may be related to secondary exposure. While HUD did not include OSHA on its task force,

occupational issues are represented through the inclusion of the Centers for Disease Control's (CDC) National Institute of Occupational Safety and Health (NIOSH), the arm of CDC which conducts research and research training related to occupational safety issues. Further, the research performed by NIOSH serves as the scientific basis for OSHA's standards settings.

DOMESTIC DISCRETIONARY REQUEST

E-1 Mr. Early: The Department's fiscal 1992 request totals \$162.265 billion. What is the Department's request for domestic discretionary programs? and what is the dollar and percentage increase over the FY 91 level for these programs?

Secretary Sullivan: The total program level for domestic discretionary programs under the jurisdiction of this Subcommittee is \$29.028 billion, an increase of \$1.323 billion or 4.8 percent over fiscal year 1991. Of this amount, \$21.150 billion was for gross increases to programs in the Department. This is a \$2.105 billion or 11.0 percent over fiscal year 1991.

Approximately 76 percent of the domestic discretionary programs received increases in fiscal year 1992.

E-2 Mr. Early: What is the total decrease for discretionary programs?

Secretary Sullivan: Total discretionary programs that were decreased or eliminated in fiscal year 1992 is \$1.751 billion, a decrease of \$1,138 billion or 39.4 percent from fiscal year 1991.

Approximately 6 percent of the discretionary programs were decreased.

E-3 Mr. Early: Why is the administration proposing a reduction in the Department's discretionary programs?

Secretary Sullivan: The Budget Agreement passed last winter set targets for discretionary programs in three categories. All discretionary programs in the Department are in the Domestic Discretionary category.

In order to have increases in vital areas, such as infant mortality, hard choices had to be made. Programs, of lesser urgency, although important, had to be cut. For every increase above inflation, there had to be a corresponding decrease.

E-4 Mr. Early: Mr. Secretary, would you give us some idea of how your Department fared compared to others in terms of the percentage increase for discretionary programs?

Secretary Sullivan: The overall increase in discretionary outlays Government-wide was 1.0 percent. HHS increases totaled 3.2 percent. The following is a list of cabinet Departments that increased at a greater rate:

<u>% Change</u>	<u>Department</u>	<u>1992/1991</u>
	Department of Justice	16.9%
	Treasury Department	9.1%
	Department of Education	9.0%
	Department of Energy	8.7%
	Department of Agriculture	7.8%
	Department of Interior	7.3%
	Department of Veterans Affairs	5.8%
	Department of State	5.0%
	Department of Labor	4.5%
	Department of Transportation	3.6%

Several cabinet Departments increased less than HHS:

Department of Defense - Civil	2.9%
Department of Justice	1.5%
Department of Commerce	—
Department of Defense - Military	-1.6%

E-5 Mr. Early: The budget justification states that "in order to meet budget targets for the FY 92 health programs, very difficult choices among priorities ... must be made." Doctor, did HHS receive a target figure — a ceiling — for health programs, or discretionary health programs from OMB? Did you set a target figure?

Secretary Sullivan: The Budget Agreement passed last winter set targets for discretionary programs for each fiscal year from 1991 through 1996. These broad targets were established using the fiscal year 1991 enacted appropriation as a base and applying an inflation factor.

No specific target was set for each program or group of programs, although the inflation factor was applied to each of the programs to calculate the total target. The HHS target for all programs was adhered to, with some programs receiving increases and other corresponding decreases.

E-6 Mr. Early: — If so, How was this target figure arrived at?

Secretary Sullivan: The overall target for Domestic Discretionary programs was set in the Budget Enforcement Act of 1990. This target was computed based on enacted appropriations for all programs Government-wide in each of the three discretionary categories.

E-7 Mr. Early: — Were target figures, or ceilings, set for other program areas?

Secretary Sullivan: Since the Budget Agreement was computed based on enacted appropriations, each program had a level that was aggregated for a total target. Within HHS we used the total target and applied increases and decreases to each of the programs from the enacted level to remain within the total HHS target.

E-8 Mr. Early: What was the aggregate budget request submitted to you from agencies in your Department?

Secretary Sullivan: The requests submitted by the operating divisions (OPDIV's) in June 1990 totaled \$31.372 billion for discretionary programs under the jurisdiction of this Subcommittee.

E-9 Mr. Early: What was the Department's request to OMB?

Secretary Sullivan: The request sent to OMB on August 30, 1990, totaled \$28.951 billion for discretionary programs under the purview of this Subcommittee. This request was prior to final Congressional appropriations and passage of the Budget Enforcement Act of 1990.

E-10 Mr. Early: Did you take any appeals on the pass-back and if so, for what programs?

Secretary Sullivan: The Department appealed the distribution of the passback received from OMB and negotiated equitable funding levels given budget constraints. A large portion of the negotiations with OMB were on methods of financing our programs, for example, user fees and other collections. Programs appealed included administrative accounts in the Health Care Financing and Social Security Administrations, infant mortality, breast and cervical cancer screening, and AIDS.

PRIMARY CARE PROGRAMS

E-11

Mr. Early: One of the budget's major domestic themes is increasing access to health care. Yet, your budget request calls for no increases in key primary care programs servicing low-income individuals such as the maternal and child health block grant and community health centers. In fact, these programs would be funded at the FY 90 level under your budget request would you comment on this?

Secretary Sullivan: Yes, increasing access to health care is a major objective of my budget. First, I would like to clarify that the Community Health Center Program will receive the entire

amount appropriated in FY 1991, an increase of \$21 million over FY 1990; and no individual grantee will receive less than it received in FY 1990. In FY 1991, the Department plans include establishing new centers, as requested in the FY 1991 Labor/HHS Appropriations Conference Report, in the target areas.

The FY 1992 budget also includes: a direct appropriation of \$139 million for Healthy Start to provide comprehensive services to women and their infants; a \$5 million increase for the National Health Service Corps Recruitment programs to ensure that more primary health care providers will be available to serve in underserved areas; and a 24 percent increase, \$12 million, to provide health care services to the homeless. It should also be noted that the recent Medicaid expansions will remove many of the financial barriers to access for low-income women and their children.

HEALTH PROFESSIONS

E-12

Mr. Early: The budget request proposes to eliminate virtually all funding for health manpower programs. No funds have been requested for primary care and family medicine residencies, allied health, public health, or geriatric training, etc. Has the shortage of these professionals ended? Why are you eliminating these programs?

Secretary Sullivan: The HRSA budget provides a request for \$127 million in direct support for health professions education programs. In addition, \$263 million is available through existing revolving loan funds and guaranteed loans. We are also seeking to recapitalize the Health Professions Student Loan program at \$15 million in FY 1992. Our objective, a common theme throughout our budget, is to focus resources in programs which target minority and disadvantaged students seeking a career in a health field and to move funding away from broad-based categorical programs.

HEALTH PROFESSIONS

E-13

Mr. Early: The budget states that funds to help students finance their training will continue to be available through Medicare medical education payments. Yet, your budget request calls for significant reductions in both indirect medical payments and graduate medical education payments (reimbursements) under Medicare. Taken together, Doctor, how will these programs affect medical schools and teaching hospitals which are under tremendous financial pressure?

Secretary Sullivan: Independent experts, including both PropAC and GAO, agree that the current indirect medical education (IME) adjustment is too high. Our proposal would phase in a more appropriate payment level over time and would eliminate excessive and unwarranted payments to teaching hospitals. Our graduate

medical education (GME) proposal would make per resident payments more uniform and would work to encourage the training of more primary care residents. We believe that a more appropriate and realistic IME and GME payment policy will provide incentives for teaching hospitals to reduce inefficient practice patterns that will help them survive in a competitive health care system.

E-14 Mr. Early: Why do you also propose to eliminate funding all nurse training programs?

Secretary Sullivan: The FY 1992 provides \$4.2 million in direct support for Disadvantaged Assistance for Nurses and the Nursing Student Loan Revolving Fund will have approximately \$13 million available to provide low interest loans to nursing students. As with other health professions programs, our budget focuses resources on minority and disadvantaged students.

E-15

Mr. Early: The HEAL program is an expensive way to finance a medical education. It is considered a financial aid program of last resort. However, for most students, borrowing through the HEAL program is unavoidable. How will your proposal to phase down HEAL affect these students, particularly since there are limits on borrowing under other programs and scholarship aid is almost non-existent?

Secretary Sullivan: You are absolutely right, the HEAL program is an extremely expensive program for students. One of the misfortunes of the HEAL program is that students leave school with such a high level of debt that it precludes them from being able to pursue a career in the underserved areas where they are needed. Therefore, to reduce the reliance of needy students on the high-cost HEAL program, our budget proposes strengthening and expanding scholarships and direct loan programs, including the Health Professions Student Loan program and the National Health Service Corps scholarship and loan repayment programs.

E-16

Mr. Early: Doctor, how could a young man or woman from a working class or middle class, family finance a medical education?

Secretary Sullivan: There are a number of different ways a student could finance a medical education. In FY 1992, HHS is requesting \$127 million in direct support for health professions programs including scholarships and loans through the National Health Service Corps, the Health Careers Opportunity Program, and the Exceptional Financial Need Scholarships. We are also seeking a \$15 million expansion of the Health Professions Student Loan Program. In addition \$263 million is available through existing

revolving loans funds and guaranteed loans. Beyond this Department, scholarship and loan programs are available through the Department of Education, the Department of Veterans Affairs, and the Defense Department. Private loans are also available.

LOW INCOME HOME ENERGY ASSISTANCE PROGRAM

E-17

Mr. Early: The President's Budget proposes a substantial reduction (-\$585 million) in the Low Income Energy Assistance Program, with a 34.6% decrease in basic LIHEAP funds. Why is such a large decrease being proposed for this program?

Secretary Sullivan: Energy assistance programs were created in the early 1970's as one of the Federal responses to the sharp increases in energy prices and the consequent immediate effect on low income households. LIHEAP, created in the early 1980's, was established to supplement other sources of assistance, not to supplant them. Many other Federal, State, and private sources supply funds for energy needs. With the overall budgetary limitations, we have had to make many priority determinations, and it is our best judgement that special energy assistance should be focused toward emergency crisis situations, and should be funded at a level of \$1.025 billion, approximately 37% less than in FY 1991. The fact that many States continue to transfer LIHEAP funds to other block grants (28 States transferred \$52 million in 1990) suggests that a reduction is warranted. In addition, The President's Budget takes into account the fact that the home energy burdens as a percent of household income for low-income households has declined between FY 1981 and 1989, from 8.0 percent to 5.4 percent, indicating a reduced need for LIHEAP in offsetting home energy costs as a percent of household income.

E-18

Mr. Early: Are you proposing any changes in the way this program would operate? In the way funds would be allocated?

Secretary Sullivan: No, funds will be allocated the same as they were allocated in FY 1991. As the Congress enacted in FY 1991, the FY 1992 budget includes an emergency contingency fund for LIHEAP. Under this proposal, an additional \$100 million would be allocated to States above the \$925 basic appropriation if the average price of home heating oil is more than 20 percent greater than the average price for the corresponding months for 1986, 1987, 1988 and 1989. We believe that the contingency fund allows the Federal government to play its appropriate role with regard to energy assistance: providing benefits only in circumstances of exceptional need.

E-19

Mr. Early: What impact will this proposal have on the number of households currently being served?

Mr. Secretary: LIHEAP is a block grant program that gives States the flexibility to determine payment levels and the number of low-income households that will be served in any given year. Because the number of households to be served is a State decision, we do not have estimates for FY 1992.

e-20

Mr. Early: How many fewer households will be served under your budget request?

Mr. Secretary: As stated earlier, because the number of households to be served is a State decision, we do not have estimates for FY 1992. States have the flexibility to adjust both payment levels and number of households served to accommodate changes in program funding from one year to the next.

E-21

Mr. Early: As you know, Mr. Secretary, a significant number of States, particularly cold weather States, are facing severe fiscal problems. And it seems highly unlikely to me that their situation is going to improve appreciably by this fall/winter. Mr. Secretary, how do you expect these States to make up such a drastic reduction?

Mr. Secretary: In addition to LIHEAP, States can provide for the energy needs of low-income households through other federal income maintenance programs. Energy assistance needs for low-income households are considered in other federal programs, including AFDC, Emergency Assistance, Food Stamps, Social Security and SSI, and HUD Housing Assistance.

With the overall budgetary limitations, we have had to make many priority determinations, and it is our best judgement that LIHEAP should be focused toward emergency crisis situations, and should be funded at a level of \$1.025 billion, approximately 37% less than in FY 1991. The fact that many States continue to transfer LIHEAP funds to other block grants (28 States transferred \$52 million in 1990) suggests that a reduction is warranted. In addition, The President's Budget takes into account the fact that the home energy burdens as a percent of household income for low-income households has declined between FY 1981 and 1989, from 8.0 percent to 5.4 percent, indicating a reduced need for LIHEAP in offsetting home energy costs as a percent of household income.

E-22

Mr. Early: One of the arguments made in defending proposed reductions in LIHEAP is that a number of States transfer funds out of this program to other block grants. Beginning in FY 1994, transfers out of LIHEAP are prohibited. What is the Department's position on eliminating this transfer out authority at an earlier date?

Mr. Secretary: During reauthorization of the LIHEAP program last year, we opposed eliminating the transfer out authority at all. We believe States should have the flexibility to transfer funds among the federal block grants to meet the particular needs of the individual State. We certainly would not support eliminating this provision a year earlier.

e-23

Mr. Early: Would the Department support a change in the program to direct funds to those funds where the need for such assistance is greatest -- that have fully utilized their funds for fuel assistance?

Mr. Secretary: We are not proposing any change in the way LIHEAP funds are allocated.

NATIONAL INSTITUTES OF HEALTH

E-24

Mr. Early: The President's Budget submission highlights the increase to \$76 billion for direct federal investment for research and development. The budget documents state that this is an increase of \$8.4 billion, or 13%. Mr. Secretary, can you tell us what portion of this 13% increase NIH and ADAMHA research received?

Secretary Sullivan: The FY 1992 President's Budget request includes a total of \$9.3 billion for research and development activities at the National Institutes of Health and the Alcohol, Drug Abuse and Mental Health Administration. This represents an increase of \$622 million or 6.3 percent over FY 1991. The increase provided for NIH and ADAMHA research and development constitutes approximately 7 percent of the total increase requested by the President for research and development government-wide.

E25

Mr. Early: How do the NIH and ADAMHA increases compare with the increases received by other R&D program?

Secretary Sullivan: The 6.3 percent increase requested for NIH and ADAMHA research is neither the highest nor lowest provided to the various federal agencies that support research and development. Among the research programs with budgets over \$1 billion, the Department of Defense research program was provided a 6 percent increase, the Department of Energy an 8 percent increase, NASA an 11 percent increase, the National Science Foundation a 13 percent increase, and the Department of Agriculture a 4 percent increase. For the smaller research programs, FY 1992 requests range from increase of 32 percent (Agency for International Development) to a decrease of 1 percent (Department of the Interior).

E-26

E27

Mr. Early: The Administration's request for NIH research is \$8.4 billion. In terms of current services levels, how much of an increase did NIH receive and how does that compare to other

science research programs? What about ADAMHA?

Secretary Sullivan: NIH's FY 1992 budget of \$8.8 billion represents an increase of 6 percent over FY 1991. Within this total, we have provided research project grants with a total growth rate of 8.8 percent, or 3 percent real growth. ADAMHA's FY 1992 request for research totals \$1.065 billion, an increase of 8.5 percent, which when adjusted for inflation represents real growth of 2.6 percent.

The rates of real growth for NIH and ADAMHA are lower than seven of the eleven other federal research programs with FY 1992 request greater than \$200 million. For those programs with requests greater than \$1 billion, three of the five would receive rates of increase higher than those requested for ADAMHA and NIH.

E-28

Mr. Early: Is there a particular reason that NIH and ADAMHA received significantly less than the average increase for science research?

Secretary Sullivan: I do not believe the President made decisions on the various federal research budgets by comparing the agencies. Instead, decisions were based on what funding levels were necessary in order to carry out the mission of each agency. In some cases, funding levels are driven by particular projects the agency is responsible for completing. In the case of NIH and ADAMHA, funding levels were developed primarily as a function of what level of real growth we could afford within the overall spending targets for the Department specifically and within the domestic discretionary budget in general. I would also note that over a two-year period, the research budgets of NIH and ADAMHA have increased almost 17 percent.

E-29

Mr. Early: What is the status of the Department's and NIH's implementation of the Senior Biomedical Research Service legislation?

Secretary Sullivan: The Department is in the process of implementing the Senior Biomedical Research Service (SERS). Because the SERS is a unique compensation system for a limited number of employees (350), there are several administrative issues which must be resolved before the SERS can be implemented. To assist in this process I have established an SERS Policy Advisory Group to lay the groundwork for implementing the SERS. The Advisory Group consists of senior staff from ADAMHA, AHCPR, CDC, FDA, and NIH. I expect to receive recommendations from the Advisory Group and other Department senior staff within the next several weeks. We anticipate being able to begin implementation of the SERS by early summer.

E-30

NIH RECRUITMENT

Mr. Early: Can you give us any indication of the impact this legislation will have in ameliorating NIH's recruitment and retention difficulties?

Secretary Sullivan: The implementation of the SERS will provide for salaries of up to \$138,000 for PHS senior scientists. The mean salary for physician researchers at medical schools is \$227,000 while the mean salary for non-physician doctorates is \$101,000. Thus, depending on pay scales established under the new pay system, SERS could result in the pay for NIH Ph.D. researchers equalling that of their academic counterparts. However, even with SERS there will remain a noticeable difference in pay between senior NIH physician scientists and many of their counterparts at U.S. medical schools, although there are tradeoffs in the type of work environments as well.

E31

Mr. Early: Will it have a significant, a modest, or a marginal effect on recruitment and retention?

Secretary Sullivan: We are optimistic that the new SERS pay plan for senior scientists will assist those PHS agencies seeking to recruit scientists. However, at this juncture, it would be premature to predict the impact that the pay plan alone will have on recruitment and retention. I wish to add, however, that while there has been much public attention directed toward the pay disparity issue, there are a number of other reasons a scientist might be attracted to a career at NIH or ADAMHA. A prominent asset is the Warren G. Magnuson Clinical Center, the largest research hospital in the world. In addition, NIH intramural scientists are not burdened with having to write grant applications and progress reports, and consequently have much more time to devote to their research.

BREAST AND CERVICAL CANCER SCREENING INITIATIVE

E-32

Mr. Early: Mr. Secretary, I was pleased to see that your budget request includes an increase of \$20.7 million for the Breast and Cervical Cancer Screening initiative -- almost doubling the FY 1991 funding level. What do you hope to accomplish with this increase?

Secretary Sullivan: Our budget request will allow CDC to accomplish several objectives. First, the request will provide funding for approximately 10 States to provide Pap smears and mammograms for low-income women who do not have any access to public or private health insurance -- adding approximately 201,000 women to the 200,000 women currently benefitting from this program. It will also support laboratory and x-ray quality assurance activities in all 50 States. Finally our request of \$50 million will enhance our surveillance activities related to breast

and cervical cancer and allow us to support additional breast and cervical education projects for women and health care professionals.

E-33

Mr. Early: Are we doing enough or do we still need to do more?

Secretary Sullivan: Until all preventable cases of breast and cervical cancer are eliminated, of course we could do more. But the budget we seek will allow us to go a long way toward improving the current situation.

E-34

Mr. Early: How can we be more effective about educating women about periodic mammograms and Pap smears and in ensuring that women avail themselves of these diagnostic tools for early detection.

Secretary Sullivan: The Federal government alone can not accomplish this task. Working together, government and the private sector, can raise the awareness of all women -- and those who care for them -- about the need for regular screening. This is happening. Last year, for example, I participated in the "Race For The Cure", a nationwide campaign to increase awareness of the need for breast cancer screening, prevention and treatment. The FY 1992 budget, as I mentioned before, includes increased resources for public and professional education. I believe we are making progress, but it will take time to get the message out, and for people to take heed of that message.

HEALTH CARE FINANCING ADMINISTRATION

E-35

Mr. Early: In October/November the Administration and Congress concluded a five year deficit reduction agreement, which included \$42.5 billion in Medicare cuts over five years. The Department's budget request is calling for an additional \$25.2 billion in Medicare reductions. A number of these proposed reductions were rejected in summit negotiations. Why are you proposing such substantial reductions in the FY 92 request when the ink is barely dry on the deficit reduction agreement?

Secretary Sullivan: The five year budget agreement does not exempt us from our obligation to continually seek to improve the programs we are charged with administering. The primary reason for these new legislative proposals is program improvement. The specific proposals we are suggesting are designed to encourage efficient and cost-effective delivery of health care, to eliminate excess and duplicate payments and to make payments more rational and consistent. It is also important to remember that we are not proposing to reduce spending for Medicare below what it is currently, but only slow the rate of growth in Medicare spending. Even with these proposed reductions, Part A outlays will grow by 7.4 percent and Part B by 11.3 percent. Without these proposed

reduction, Part A outlays would grow by 10.5 percent and Part B outlays by 13 percent.

E-36

Mr. Early: The operating margins of hospitals have been declining sharply over the last several years, with more hospitals closing their doors each year. Many hospitals are reporting that they are already losing money on Medicare patients, in addition to losses they sustain for providing uncompensated care to the uninsured and for Medicaid patients. What impact will these cuts have on the financial viability of hospitals and their ability to provide access to and quality care?

Secretary Sullivan: Our most recent data indicate that, while actual hospital profit margins on Medicare declined during the fifth year of the Prospective Payment System (PPS) (1987-1988), the last year for which we have data, they still averaged 2.19 percent, despite an overall national hospital occupancy rate of only 60 percent. However certain classes of hospitals have fared very well under PPS and there still remain subsidies in the hospital system that are clearly excessive. We believe that there are still efficiencies that can be achieved and our savings proposals are designed to correct some of the problems in Medicare payments to hospitals.

E-37

Mr. Early: Isn't this going to cause health care providers to further shift costs onto private payors?

Secretary Sullivan: Without our proposed reductions, Medicare outlays would continue to grow by over 7 percent. We have a responsibility to the taxpayer to continually seek to improve the Medicare program and contain excessive costs wherever possible. We have evidence that Medicare is providing subsidies, particularly in teaching hospitals, to non-Medicare patients. While we can not predict the extent to which health care providers may or may not shift costs onto private payors, we do know that Medicare alone can not bear the burden of cost control. Hospitals must be encouraged to cut excessive spending and adopt more efficient practice patterns so that reforms in the Medicare program will not result in cost shifts to other payors.

E-38

Mr. Early: Is there any evidence that Medicare reductions made to date have slowed down the rapid escalation of overall health care costs throughout our society?

Secretary Sullivan: The Medicare Prospective Payment System (PPS) has been very effective in slowing down the growth in overall Medicare payments to hospitals since 1983. We believe that this has contributed to more efficient and cost effective practices by hospitals. To the extent that hospitals operate more efficiently, this has resulted in some decrease in overall health care expenditures. However, Medicare still only accounts for a

portion of total health care expenditures and Medicare alone can not assume the total burden of health care cost control.

E-39

Mr. Early: The budget request also proposes imposing a 20% copayment on clinical laboratory services. Isn't this going to increase the costs paid by Medicare beneficiaries?

Secretary Sullivan: This proposal needs to be viewed in the context of the coinsurance changes we are proposing for services in outpatient departments. Those changes will save beneficiaries money. The net effect of the coinsurance changes on beneficiaries is considerably less than the actual budget effect of the proposal. Additionally, most Medicare beneficiaries have supplemental insurance or are covered by Medicaid, which will pay this additional coinsurance. Thus, most beneficiaries will not be paying any additional out-of-pocket costs. It is also important to note that this proposal is consistent with all other Part B services, which currently all have a 20 percent coinsurance.

E-40

Mr. Early: What is the estimated out-of-pocket cost to beneficiaries of this proposal in the first year?

Secretary Sullivan: We anticipate that the total impact of this proposal will be savings of \$450 million in FY 1992. However, the actual impact on any given individual beneficiary would depend upon a number of factors including; the number and nature of clinical laboratory services they receives, the type of additional insurance they have, and the amount of savings they realize as part of the outpatient savings proposal.

E-41

Mr. Early: Over a five year period?

Secretary Sullivan: Over five years we expect savings of over approximately \$4.3 billion.

E-42

Mr. Early: The financial status of the nation's teaching hospitals has declined markedly during the 1980's. A growing percentage of major teaching hospitals are now operating at a loss --- increasing from 18.2% in FY 84 to 33.0% in FY 88. Would you generally agree with this?

Secretary Sullivan: Although total margins for teaching hospitals have been declining, it is important to note that Medicare profit margins for teaching hospitals have exceeded those for non-teaching hospitals by consistently wide margins since the beginning of PPS in 1983. Our most recent data show that the average Medicare profit margin for hospitals with a heavy teaching load was 12.37 percent and 3.58 percent for hospitals with a light teaching load compared to -1.66 percent for hospitals with no teaching. This can be compared to the overall national hospital Medicare margin of 2.19 percent.

E-43

Mr. Early: It is my understanding that one of the major reasons the financial condition of major teaching hospitals is so bleak is that these hospitals tend to be in the inner city and serve a disproportionate share of the poor and uninsured. In general would you agree?

Secretary Sullivan: Yes, I would generally agree that these are among the components that can lead to a bleak financial situation for some hospitals.

E-44

Mr. Early: This being the case, could you explain why 61% of the cuts in hospital reimbursements (\$9.7B) are being targeted on the nation's teaching hospitals? Have you analyzed the impact of these cuts on these hospitals and the effects they will have on their financial stability or viability? Ability to serve the poor and uninsured?

Secretary Sullivan: Independent experts in the field (both PropAC and GAO) agree that the Indirect Medical Education (IME) adjustment is too high. Our proposal to gradually cut this adjustment would still adequately compensate teaching hospitals for the costs associated with training interns and residents, but would eliminate excessive payments to these hospitals. Recent data from a PropAC study indicate that there is no relationship between IME payments and how much a hospital spends on uncompensated care for the poor and uninsured. Thus, reducing the level of the IME adjustment should have no greater impact on hospitals that treat a large number of poor patients than on those that don't treat poor patients. Hospitals do receive payments specifically intended to compensate them for serving low income Medicare patients through the disproportionate share adjustment.

We do not anticipate that these proposed reductions will affect the quality of or access to health care for Medicare beneficiaries. We do hope that the reductions will provide incentives for teaching hospitals to reduce inefficiencies.

E-45

Mr. Early: Is it accurate to say that the President's budget request funds health care programs at less than would be needed to offset inflation and maintain current services --- Even by OMB own estimates?

Secretary Sullivan: We are not proposing to reduce spending for Medicare below current levels, nor are we compromising beneficiary access to quality health care or reducing their benefits in any way. Current Medicare Part A growth in outlays would be 10.5 percent without any savings proposals. Even with our savings proposals Part A growth is expected to be over 7 percent. Part B growth is currently expected to be 13 percent and still over 11 percent with our savings proposals.

INFANT MORTALITY

P-1

Mr. Pursell: The Administration has requested \$34 million in reprogrammed FY 91 funds and \$139 million in new funding for FY 92, to conduct a demonstration project in selected cities where infant mortality rates are excessively high. This committee has provided \$25 million in new funding in the FY 91 supplemental appropriations bill. If the final bill includes \$25 million, will the Administration amend its \$139 million request?

P-2

Secretary Sullivan: Our FY 1992 budget request of \$171 million for Healthy Start is the first full year funding for what we believe is a four to five year involvement in high incidence communities. Our plans for a comprehensive attack on this problem tell us that the full \$171 million can be well spent.

P-3

Mr. Pursell: When will the Department provide details of the proposed demonstration projects?

Secretary Sullivan: We are planning to publish a grant announcement in early April which will provide grantees with the details necessary to apply. We are also planning several bidders' conferences to make technical assistance available to applicants.

P-4

Mr. Pursell: The availability of care is not the only factor responsible for high infant mortality rates, and it is good that the Department intends to examine social and non-financial barriers. How do you plan to involve local community support groups in the demonstrations?

Secretary Sullivan: Integrating community support and social services with primary prenatal care is a crucial component of the Healthy Start program. To be eligible to receive a Healthy Start grant, a community will have to demonstrate that it has community support and involvement. We are looking forward to seeing the innovative approaches that communities will undertake to create a comprehensive system of care.

Mr. Pursell: High infant mortality rates are also a problem in many of our nation's rural communities. Does the Department have any plans to conduct special demonstration projects in these areas anytime soon?

Secretary Sullivan: I share your concern for rural areas and rural areas will be eligible to compete for Healthy Start funds. In addition, the Department has funded, and continues to fund, projects on infant mortality in rural areas through the Maternal and Child Health Block Grant set-aside funds (SPRANS) and the Office of Rural Health.

BREAST AND CERVICAL CANCER SCREENING

P-5

Mr. Pursell: The Department is requesting \$50 million, a 70% increase, for breast and cervical cancer screening programs. If these activities are funded at this level, how many states will receive funding for their programs?

Secretary Sullivan: Approximately ten.

P-6

Mr. Pursell: As you know, the qualifications of some of the people involved in breast and cervical cancer screening programs has been a great concern to many health advocates, including Members of Congress. Does the budget request include funding for quality assurance in breast and cervical cancer screening programs?

Secretary Sullivan: As part of OBRA 90 Medicare will provide coverage of screening mammography. We are very concerned about ensuring the safety and effectiveness of mammography for Medicare beneficiaries and have included very strict standards in the recently published regulation. Specifically, screening mammography must be performed by an individual licensed by the State and must be interpreted by a certified physician.

HCFA has asked the approximately 9,000 screening mammography clinics participating in the Medicare program to provide a statement of self-attestation that quality services are being provided. In FY 1992, HCFA has included \$4.5 million as part of the survey and certification budget to cover the costs associated with ensuring high quality mammography screening. This funding level will allow HCFA to survey the 9,000 self-attested screening mammography clinics, plus provide additional funding for an anticipated 2,000 new screening mammography clinics requesting participation in the Medicare program.

P-7

Mr. Pursell: The Administration and Congress have supported large increases in Head Start appropriations for the past two fiscal years, and the Administration is requesting a \$100 million increase in FY 1992, to \$2.1 billion. This would enable Head Start to serve an additional 30,000 children in FY 1992. What percent of eligible children are being served now?

Secretary Sullivan: In FY 1991, we will be serving 56% of all eligible children for at least one year before they enter school. With our FY 1992 request, this number increases to 59%.

P-8

Mr. Pursell: How many children will remain unserved in FY 1991?

Secretary Sullivan: We estimate that approximately 365,000 low-income children who will enter kindergarten in the following year remain unserved by Head Start. However, we also estimate that 20% of eligible children, or 165,000 children, are participating in other programs, or are not interested in Head

Start. Therefore, we estimate that 200,000 children remain to be served beyond FY 1991.

P-9

Mr. Pursell: The budget request includes 50 new staff positions to support Head Start and a 37 percent increase for travel. This is a large increase considering that the budget request for Head Start is only about five percent higher than this year's appropriation.

What would these funds be used for?

Secretary Sullivan: Adequate management support for Head Start is critical to the success of the ongoing expansion program. The FY 1992 budget provides an additional 48 Federal staff positions for Head Start, mostly in the OHDS regional offices to perform program and fiscal management, technical assistance and monitoring activities essential to maintaining program and fiscal standards during the major enrollment expansion. We have also provided the necessary travel dollars to allow regional staff to monitor and provide adequate technical assistance to new and expanding grantees. Head Start is now required to monitor at least one-third of its over 1300 grantees each year according to the recently enacted amendments to the Head Start Act.

P10

Mr. Pursell: Did the Administration request FTE and Travel increases for FY 1990 and FY 1991 when the Head Start program was significantly expanded?

Secretary Sullivan: The Administration did not request significant increases for staff and travel in the President's Budgets for FYs 1990 and 1991.

Mr. Pursell: Last week, an FDA advisory Committee surprised many in the health community when it voted not to provide "fast-track" approval of the Alzheimer's drug tacrine (or THA). We are all aware of the FDA's past problems, and I believe it is generally on the right track, but I hope that fast-track approval of new drugs is receiving full consideration.

When FDA reviews a drug, are the drug's benefits given the same consideration as the adverse affects?

Secretary Sullivan: FDA drug reviews are designed to ensure that drugs are both safe and effective prior to marketing. The agency has long realized, however, that the adverse affects of a particular drug must be weighed against the drug's benefits, particularly if no alternate therapy is available. More recently, FDA has come to realize that the risk of shortening the traditional three phase drug testing process is sometimes justified for patients who are desperately ill, provided that the information generated by the traditional testing procedures is still provided. Through Treatment Investigational New Drug (IND) regulations and the new parallel track initiative, FDA is providing AIDS and cancer patients with drugs at the same time as

these drugs undergo the traditional review process. New expedited review procedures, involving collaboration between FDA and the manufacturer in the drug testing process, have also been successful in cutting drug development times by as much as one-half.

P-12

PHYSICIAN PAYMENT REFORM

Mr. Pursell: What is the status of the implementation of physician payment reform?

Secretary Sullivan: We are moving forward on schedule with the necessary steps for implementation of physician payment reform. The Model Fee Schedule was transmitted to Congress on August 31 last year and was published in the Federal Register in early September. Comments received on it were useful in developing the actual fee schedule. We anticipate publishing the Notice of Proposed Rule Making on the fee schedule soon and the Final Rule in October.

P-13

Mr. Pursell: Is this on schedule for next year?

Secretary Sullivan: We are fully confident that every thing will be in place for the beginning of the implementation of physician payment reform on January 1, 1992, as required by law.

P-14

CENTERS FOR DISEASE CONTROL BUDGET

Mr. Pursell: The budget request for CDC amounts to only 8% of the Public Health Service budget. Is this sufficient to help meet the Healthy People 2000 goals?

Secretary Sullivan: You are quite right in observing what portion CDC represents of the total PHS request. You will note, however, within the CDC request that there are significant increases for programs which will directly affect Healthy People 2000, including a 16% increase for the Preventive Health Block Grant, a 42% increase for breast and cervical screening, and an almost doubling of the lead poisoning request. Many of these resources will be enhanced with State and local funding. In addition, we are proposing a 21% increase for the National Center for Health Statistics, the organization which will help us measure progress in meeting our goals.

P-15

DURABLE MEDICAL EQUIPMENT

Mr. Pursell: The Administration is proposing cuts in durable medical equipment (DME), in addition to the \$2 billion in cuts over a five year period required in OBRA '90. Every year prior to reconciliation, I am contacted by DME providers in my state, and they are increasingly concerned that they will be unable to continue to provide DME services to Medicare beneficiaries.

Do you believe the additional proposed cuts are prudent, since any long-term care policy must include a strong home care component?

Secretary Sullivan: We are proposing to recalculate the way we pay for DME in an effort to achieve more cost effective delivery of these services. There is extremely wide variation in the fee schedule amounts for DME which can't be explained by geographic cost differences. Our proposals will help to make payment for DME more reasonable across locations. We do not believe these DME proposals will have any adverse impact on beneficiaries who receive services in their homes nor will they have any impact on future long term care proposals.

P-16

Mr. Pursell: Why is HHS proposing to use the national median rather than the national weighted average as the basis for the national payment limitation and floor for DME?

Secretary Sullivan: There is extremely wide variation in the fee schedule amounts for DME. Variation between States and regions do not fall into a logical pattern and payment amounts are frequently very different for the same item in neighboring locations. The OBRA 90 policy to place a national payment limitation and floor on fee schedule amounts based on the weighted average will help to limit the extreme degree of variation. It would be more appropriate, however, to base the payment limitation on the median rather than the weighted average of the fee schedule amounts. If one half of all carrier areas are able to provide the items at prices below the median, it is reasonable to expect the other half of the areas to provide items for no more than that median amount. Using the median would further help to rein in the substantial and unexplained variation in the fee schedules while still maintaining a sufficient degree of variability to allow for geographic cost differences.

FO-1

TITLE X

Mr. Porter: Dr. Sullivan, does the Administration support the reauthorization of the Title X program?

Secretary Sullivan: Yes, the Administration continues to propose the reauthorization of Title X as a Federally financed, state administered program. State administration would provide increased flexibility to meet local needs and priorities and would allow for better integration with related services including prenatal care, maternal & infant health care, and drug abuse services. Under the Administration's proposal, certain basic requirements of Title X would be retained, including the requirement that low-income families be given priority, that acceptance of services be voluntary, and the prohibition on the use of Title X funds in programs where abortion is a method of family planning.

FO2

NATIONAL MUSEUM OF HEALTH AND MEDICINE

Mr. Porter: The National Museum of Health and Medicine is currently located at Walter Reed Army Medical Center, but is planning to upgrade and relocate its current facilities. I understand that you have personally visited the Museum and that former Surgeon General Dr. Koop is leading the effort to move the Museum to the Mall. Can the Museum fulfill an important objective in educating the public about health issues?

Secretary Sullivan: Improving science education in this country and increasing public scientific literacy is one of our national goals. An expanded National Museum of Health and Medicine is a potentially powerful and effective mechanism for achieving this goal.

FO-3

Mr. Porter: When the Health Museum was located on the Mall, 25 years ago, it was the most visited of museums on the Mall. Won't a federal investment in the public-private partnership pay long-term dividends in health education?

Secretary Sullivan: I really cannot comment on the financial plans for the Museum, because we are not certain as to the nature of the federal investment that the National Museum of Health and Medicine Foundation envisioned. I would, however, note that while the Foundation is considering the Great Hall of the Hubert H. Humphrey Building as a potential location for the Museum, the Department has no near or long-term plans that would include a museum being co-located in this facility.

REFUGEES

FO-4

Mr. Porter: Dr. Sullivan, in the Family Support Administration you have requested only level funding. Why?

Secretary Sullivan: The FY 1992 President's Budget includes

\$411 million for the Refugee Resettlement, the same as the FY 1991 level. This level of funding will provide resettlement assistance to 120,000 new refugee entrants. This is the same level refugee entrants anticipated by the State Department for FY 1992.

PO-5

Mr. Porter: You have also eliminated the line items for refugees. Why have you done that?

Secretary Sullivan: We have no intention of eliminating the line items for the Refugees program. We expect to provide the Committee with a proposed distribution by activity in May when we have more information on States' current FY 1991 expenditures.

PO-6

Mr. Porter: Are you trying to alter the program configuration as it was authorized and as it has been implemented in the past?

Secretary Sullivan: By submitting an "undistributed" budget for Refugees, our intention was not to alter the program in any way. We fully intend to provide the Committee with a proposed distribution when we have more information on FY 1991 expenditures, refugee flow, service needs and participation rates.

PO-7

Mr. Porter: Won't the proposed "block granting" of the refugee program simply reduce accountability?

Secretary Sullivan: Again, we are not proposing to "block grant" this program. We expect to provide the Committee with a proposed distribution by activity in May when we have more information on States' current FY 1991 expenditures.

PO-8

Mr. Porter: Specifically, what are your plans for the Matching Grant Program?

Secretary Sullivan: Again, we will provide a detailed Distribution by budget activity to the Committee in May.

ALZHEIMER'S DISEASE

R-1

Mr. Roybal: On January 11, 1991, Senator Hatfield and I jointly sent you a letter regarding State Alzheimer's Program demonstrations that were passed into law near the end of the 101st Congress (P.L. 101-557). Our purpose in writing to you was to request that the Department proceed with the funding of the State Alzheimer's Program demonstrations at the \$7.5 million level for FY91.

Since neither Senator Hatfield nor I have received an answer from you, can you tell me if our request has been honored?

Secretary Sullivan: Because the National Institute on Aging (NIA) does not have the authority to administer the Alzheimer's State Demonstrations program (this is a Health Resources and Service Administration authority), the NIA will not make awards under this authority in 1991. However, we are fulfilling your request to provide health care services to Alzheimer's patients through NIA's recently launched Alzheimer's Disease Satellite Centers Program which provides services equivalent to those that could be provided by the State Alzheimer's Program. Services available under the NIA program include an aggressive outreach program to underserved populations, diagnostic services, access to clinical trials, family consultation, and public education. The NIA program has the added benefit of providing these services with a research component that will allow us to better understand how to improve the care of Alzheimer's patients

There are four pilot Satellites at present with approximately 15 additional ones under development. The level of support that NIA will devote to this effort will exceed the \$7.5 million you requested we invest in the State Alzheimer's Demonstrations.

R-2

Mr. Roybal: In your 1992 budget, you propose additional funding for AIDS biomedical research but fail to propose any significant correction to the huge underfunding of Alzheimer's research.

Would you support giving Alzheimer's research funding parity with funding (\$650 million to \$1.5 billion) for the other major diseases (heart disease, cancer, AIDS)?

Secretary Sullivan: The FY 1992 request of \$349 million for the National Institute on Aging represents an increase of 7.7% over 1991. Of this total, NIA has budgeted \$163 million for Alzheimer's Disease research, an increase of 5.2% over 1991 and 73.4% over 1990. In total throughout the PHS, we estimate we will spend \$240 million on Alzheimer's Disease in 1992. In comparison, the 1992 budget request includes a 5.8% increase for NIH AIDS research, a 5.6% increase for the National Cancer Institute, and a 7.3% increase for heart and vascular disease research.

While I agree that more research needs to be done on Alzheimer's Disease, the current fiscal climate requires us to make a number of difficult choices. The President and I agreed on a budget for NIH which provides an aggregate increase of 6%. We also agreed to provide NIH with substantial discretion with respect to how to divide these resources among the twenty appropriation accounts which comprise the NIH. In making budget allocations, NIH has employed their best scientific judgement as to what scientific opportunities would be at hand as well as what constitutes a balanced allocation of resources among Institutes and Centers.R-3

R-3 Mr. Roybal: Would you at least support going from the current \$235 million level to either \$300 million level recommended by the Alzheimer's Advisory Panel or the \$500 million level recommended in my CARE Alzheimer's bill and by the National Alzheimer's Association?

Secretary Sullivan: Again, I agree that we need to do more on Alzheimer's Disease. I believe the 1992 budget request will allow us to continue the steady progress we have made to date. However, it is difficult to identify an ideal level of spending for Alzheimer's disease without considering the impact such a funding level would have on the rest of the programs of the National Institutes of Health, the Public Health Service, and the Department as a whole. The current fiscal climate necessitates that funding decisions be made within the context of the entire budget.

R-4 Mr. Roybal: Recent press reports have highlighted wandering as a common problem of memory impaired persons, particularly those suffering from Alzheimer's Disease.

With an estimated 4 million Americans afflicted with Alzheimer's, has the Department investigated the nature and extent of this problem?

Secretary Sullivan: Yes we have. The National Institute on Aging recently supported a small study of 106 Alzheimer's disease patients. The study found that about one-quarter of Alzheimer's disease patients were reported by family members to wander. The study also found that half of those afflicted with Alzheimer's disease experience periods of restlessness. The frequency with which Alzheimer's disease patients wander is probably affected by the stage of the illness and their living environment. Consequently, to determine the prevalence of wandering among the entire Alzheimer's disease population will require further research on larger, more representative populations.

R-5 Mr. Roybal: Has the Department supported any studies demonstrating successful strategies for reducing the risk of memory impaired individuals wandering?

Secretary Sullivan: The National Institute on Aging, in

collaboration with the National Center for Nursing Research and the Alzheimer's Association, has initiated a research program to determine how to manage symptoms of Alzheimer's disease such as wandering and other behavioral problems. In response to an NIA issued Request for Applications (RFA), NIA expects to award 7 to 10 research grants for studies aimed at identifying the factors underlying the behavioral symptoms of Alzheimer's related problems such as wandering. The studies will also seek to develop the better means of diagnosis and treatment for these problems.

R-6

Mr. Roybal: Are you familiar with the Alzheimer's Alert Program sponsored by the Helmsley Foundation and local Alzheimer's Association chapters?

Secretary Sullivan: I have recently been made aware of the work of the Alzheimer's Alert Program. I understand that they are utilizing an identification system employing ID bracelets similar to the Medic Alert bracelets used by many individuals, and that a trial program has been initiated in New York City. The identification system is designed to speed identification and safe return for people who wander, are lost, and can not adequately identify themselves.

MEDICARE BENEFICIARY ASSISTANCE ACT

R-7

Mr. Roybal: On January 17, 1991, Congressmen Rinaldo, Regula and I wrote you a letter referencing the Omnibus Budget Reconciliation Bill. In October 1990, there is the requirement that a Medicare Beneficiary Assistance Program be established in the Department of Health and Human Services in FY 1991. Since we have yet to receive an answer from you, what can you tell us about your efforts to fund and implement, at least at a start-up level, the Medicare Beneficiary Assistance Program in FY 1991?

Secretary Sullivan: Under current fiscal limitations we are currently unable to implement every aspect of the Beneficiary Assistance Program as developed in the statute. However, we are committed to meeting the objectives of the program through improvement of existing efforts. Improving beneficiaries' understanding of Medicare is an important priority which we are pursuing within budgetary constraints.

R-7

For example, one of the outreach efforts underway includes an extensive publications improvement effort. HCFA is working closely with beneficiary organizations to increase comprehension of the Medicare Handbook, the Explanation of Medicare Benefits and the Guide to Health Insurance for People with Medicare. We are working with existing State beneficiary counseling programs to develop training materials for States that do not currently have counseling programs. These programs offer one-on-one volunteer counseling about Medicare and Medicaid and are tailored to meet local needs. Additionally, instructional videos are being distributed widely to offer information to beneficiaries and our Medigap hotline continues to address beneficiary concerns.

R-8

Mr. Roybal: What are your plans for pursuing funding for this program in FY 1992?

Secretary Sullivan: We have not specifically requested funds in FY 1992 for this activity. We will be strengthening our current strategy and working within the Department to develop and assess additional plans to implement this program.

MEDICARE COVERAGE OF CERTAIN LIVER TRANSPLANTS

R-9

Mr. Roybal: On March 8, 1991, I wrote a time sensitive letter to you concerning the Department's progress on Medicare's coverage of certain liver transplants. Since I have yet to receive an answer from you, what can you tell the Committee concerning your efforts to facilitate beneficiary's access to this benefit?

Secretary Sullivan: I certainly share your concerns about the publication of this particular regulation. The final rule, which announces Medicare coverage of liver transplants under certain circumstances, is currently undergoing final clearance in the Department and should go to OMB for clearance shortly. Although the final Rule has not been published, it is important to note that the rule contains a provision that makes payment retroactive for approved hospitals to the date of the proposed rule - March 8, 1990.

HEALTH CARE SYSTEM REFORM

R-10

Mr. Roybal: In June 1989, you appointed the Quadrennial Advisory Council on Social Security and a Department Task force, headed by Under Secretary Horner to study the problems and issues concerning the uninsured and long term care.

Why has there been such a long delay from both groups in submitting their reports and recommendations concerning the uninsured and long term care.

Secretary Sullivan: This is quite a formidable task given the complexity of the health care system, the range of conflicting economic and other interests its participants hold, and the diversity of views on health care reform.

We need to reach a consensus on the goals we as a society have for our health care system, the role of the patient, the provider, the insurers, taxpayers and other payers, and government in health care, and the nature of the current system's problems. The consequences of failing to achieve consensus are all too well and recently exemplified by the 1989 enactment and 1990 repeal of the Medicare Catastrophic Coverage Act. If we cannot agree on the problems, we will not create a base of agreement for solutions.

Before a solution can be reached, we have to move the debate

from "the uninsured" to "access" -- real and effective access for the poor, the non-poor; those living in urban areas and those in rural areas; the insured and the uninsured. Until policy makers stop being preoccupied with and diverted by the symptom -- insurance and its lack -- we will fail to turn to the underlying issue: assuring access to quality care for all our people.

In order to avoid prematurely narrowing the range of approaches that the Administration might actively consider, we continue, for the time being, to be wide-ranging and eclectic in discussions with interested and expert parties, in stimulating broad national dialogue, and in weighing the ideas advanced by experts and study groups.

R-11A

CENTRAL CITY AND RURAL HEALTH CARE

Mr. Roybal: What specific changes have been targeted by the DHHS and the Office of Rural Health to positively affect rural health care access and quality?

Secretary Sullivan: We hope that all of our rural health initiatives will positively affect access to health services and result in improved quality of care for rural citizens. The FY 1992 budget request includes an estimated \$404 million specifically for this purpose -- \$336 million to provide health services to rural communities and \$68 million to support research which will evaluate the unique circumstances facing providers and consumers of rural health care.

In FY 1992, we continue to support increasing the number of health professionals deployed to rural communities through expansion of the National Health Service Corps. An increase of \$5 million will enable the NHSC to maintain health care providers in approximately 1,440 rural Health Professional Shortage Areas (HPSA) and place an estimated 521 primary care physicians in rural assignments. In addition, we view the role of State Offices of Rural Health as critically important for coordinating services for States in order to maximize the benefits gained through various programs serving rural constituencies.

Although the FY 1992 budget request does not include significant funding increases for rural health programs, I am wholly committed to the President's Rural Economic Development effort involving representatives from the private sector (CEOs), and State and Federal governments. As part of this initiative, I plan to work very closely with the Secretary of the Department of Agriculture on issues of health and social services and believe this White House effort potentially holds the key to solving the health care crisis for rural communities.

r-11b

Mr. Roybal: While a lot of attention has been focused on hospitals, what has been done for ambulatory care, nursing homes, home care and emergency medical services?

Secretary Sullivan: Some of our focus has already shifted to non-hospital based health services delivery. For instance, the Rural Health Outreach Grant program will assist provider and community consortia in developing new and innovative strategies for providing health care to rural populations. Also, the Office of Rural Health Policy (ORHP) has just completed a brochure on the Rural Health Clinics program which will be distributed soon. This brochure describes how a provider can become a participant in the program and lists necessary HCFA regional contacts.

In May of 1990, the ORHP distributed the results of a study on Emergency Medical Services to State Emergency Medical Services organizations, to the Congress, and to State Offices of Rural Health. The report distributed examines the adequacy, the availability, and the coordination between State and Community EMS providers and furnishes recommendations for improving these services. Also, the special circumstances faced by rural home health agencies and nursing homes will certainly be evaluated in demonstrations or research done regarding what makes these providers viable.

ALCOHOL, DRUG ABUSE AND MENTAL HEALTH BLOCK GRANT

R-12

Mr. Roybal: Given that most experts feel the elderly are still underserved, what Federal actions will the Administration take this year to adequately meet the mental health care needs of our elderly population?

Secretary Sullivan: The National Institute of Mental Health is conducting research in a number of areas specific to elderly Americans. Research is addressing the origins, diagnosis, and treatment of Alzheimer's Disease. Research is also being conducted looking into depression in the elderly, memory processing changes with age, and schizophrenia in the elderly.

R-13

Mr. Roybal: What percentage of the Alcohol, Drug Abuse and Mental Health Block Grant funding was set-aside for elderly mental health services? If no set-aside was made, why not?

Secretary Sullivan: There is no set-aside for elderly mental health services in the Alcohol, Drug Abuse and Mental Health Services (ADMS) Block Grant. The Anti-Drug Abuse Act of 1988 established specific set-asides in the ADMS Block Grant but did not include one for elderly mental health services. Any additional set-asides would require legislative change.

LONG TERM CARE PERSONNEL TRAINING

R-14

Mr. Roybal: With the Administration's major cut back in HRSA's health professions training, how will the Department ensure that personnel who are badly needed within the long term care settings (nursing homes, home care and community-based long term care) receive training?

Secretary Sullivan: The HRSA budget provides a request for \$127 million in direct support for health professions education programs. In addition, \$263 million is available through existing revolving loan funds and guaranteed loans. We are also seeking to recapitalize the Health Professions Student Loan program at \$15 million in FY 1992. Our objective, a common theme throughout our budget, is to focus resources in programs which target minority and disadvantaged students seeking a career in a health field and to move funding away from broad-based categorical programs.

QUALITY ASSURANCE IN HEALTH CARE

R-15.

Mr. Roybal: Given that Medicare quality assurance has now been extended beyond the hospital setting, what specific actions are being taken by the Department to implement a full program of health care quality assurance in the following health care settings: nursing homes, home health agencies, ambulatory health care and Health Maintenance Organizations?

Secretary Sullivan: Tremendous improvement has been made in recent years in the area of health care quality assurance. HCFA has been at the forefront of initiatives to enhance health care quality. Peer review organizations (PROs) are Medicare's principal vehicle for monitoring the quality of inpatient hospital services provided to beneficiaries. Recent legislation -- specifically COBRA, OBRA 86, and OBRA 87 -- imposed a number of new functions and workloads on PROs. The key provisions of these changes expanded PRO review from primarily inpatient hospital cases (that is, Medicare Part A) to include review of ambulatory and other outpatient services covered under Part B of the Medicare program. PROs are also responsible for reviewing the quality of services provided to Medicare beneficiaries enrolled in HMOs. HCFA requires PROs to review a random sample of "no-pay" bills for HMO services that hospitals are required to send to fiscal intermediaries for processing.

In addition, the State Survey and Certification program is an integral part of both the Medicare and Medicaid programs. All providers and suppliers, including hospitals, nursing homes, home health agencies, and hospices, are eligible to be paid for services rendered to Medicare beneficiaries and Medicaid recipients if they receive a certification that Federally prescribed conditions and standards of health safety and quality have been met. Payment is provided only to those providers and suppliers that possess certification. Certification provides assurance to Medicare beneficiaries and Medicaid recipients that products and services offered by certified providers and suppliers will be delivered at an acceptable level of quality.

R-16

Mr. Roybal: Are assessments of structure, process and outcome measures being included in each of these settings?

Secretary Sullivan: Assessments of facility structure and processes have historically been an integral part of the survey

and certification program. Currently, as mandated by OBRA 87, HCFA uses assessments of outcome only in the nursing facility and home health agency survey processes. These facility types constitute approximately 62 percent of the non-laboratory facilities requiring survey and certification in FY 1992. In the case of hospitals, HCFA currently relies on assessments made by the Joint Commission on Accreditation of Health Organizations (JCAHO) for assurances that quality health services are being delivered. In the case of laboratories, the Clinical Laboratory Improvement Act of 1988 (CLIA 88) mandates the use of proficiency testing for assurances that quality laboratory testing is being performed by laboratories.

In addition, HCFA is working closely with the Agency for Health Care Policy Research (AHCPR) within the Public Health Service to develop and support health services research on the outcome, effectiveness, and appropriateness of health care services used in the prevention, diagnosis, treatment, and clinical management of diseases, disorders, and other health conditions. AHCPR's FY 1992 budget of \$122 million will support research and analysis in such areas as medical liability, improvements in primary care, infant mortality prevention, and service delivery to individuals with AIDS. Once HCFA and AHCPR have gathered and analyzed the results of this research, outcome measures can be developed. These outcome measures can then be incorporated into the survey and certification activities of State agencies for their evaluation of the effectiveness and appropriateness of health care services in all types of health facilities.

HEALTH MAINTENANCE ORGANIZATIONS

r17

Mr. Roybal: What problems (i.e., marketing, financial solvency, provider payments, beneficiary complaints, selective enrollment and disenrollment) are being encountered in the use of HMOs?

Secretary Sullivan: The Health Care Financing Administration (HCFA) has encountered potential marketing abuses among Florida Medicare HMO contractors and among Humana health plans outside of Florida. In addition to HCFA's monitoring of these problems, The Department's Office of the Inspector General and the General Accounting Office are looking into potential marketing abuses among Florida's risk-based HMOs.

Humana Medical Plan (Florida) is the largest Medicare risk-based contractor in the country, with almost 20,000 Medicare enrollees. A HCFA monitoring report, released November 2, 1990, cited deficiencies of the Humana Plan in South Florida: administrative and managerial arrangements, utilization controls and quality assurance related to data generation, disenrollment process, claims processing related to timeliness standards, emergent/urgent claims payment (i.e., to non-contracted

providers), and deficiencies in the required Medicare appeals/reconsideration process. Humana submitted a corrective action plan on January 25, 1991, to correct the above-cited deficiencies, and in particular to improve Medicare marketing practices (including prevention of fraudulent enrollment). HCFA has accepted this corrective action plan and will monitor Humana's compliance through periodic reports in all areas of concern.

HCFA's concern over potential marketing abuses has led to an effort by the industry, encouraged by HCFA, to develop marketing standards that all Medicare HMOs will adhere to.

R-18

Mr. Roybal: What oversight has been conducted to assure that beneficiaries receive quality health care within HMOs?

Secretary Sullivan: All Medicare-contracting HMOs/CMPs are subject to a biennial on-site review that includes a review of the contractor's quality assurance system, availability and accessibility of care and the adequacy of grievance and appeals procedures. If deficiencies are found, the contractor must submit a corrective action plan. HCFA continues to monitor the contractor until deficiencies are corrected. On-site reviews may also be conducted on a more frequent basis if problems are reported.

The Peer Review Organization (PROs) under contract with HCFA review the clinical quality of care provided to Medicare beneficiaries enrolled in HMOs/CMPs with risk-based contracts. The PROs are also required to respond to any Medicare HMO/CMP enrollee complaints about the quality of care HMO/CMP.

In 1990 HCFA modified its PRO data reporting requirements to facilitate access to case-specific data by HMO. HCFA has begun to develop a process of routine linking of PRO findings and compliance data. A revised PRO review process that HCFA has proposed will provide more reliable and accurate data which will be linked routinely with other compliance data related to quality assurance. Completion of the project to link the data is a HCFA 1991 priority.

HCFA has completed a survey of over 17,000 Medicare beneficiaries who disenrolled from risk HMO/CMPs during the first six months of 1989. The purpose of the survey is to understand the reasons for disenrollment, whether the beneficiaries were encouraged to disenroll to receive needed medical services and whether they disenrolled due to a perceived need for medical services. If the data indicate that problems exist, the survey will assist in developing a standard monitoring approach to disenrollments. HCFA provided the survey information to Brandeis University for analysis. A draft report is due in the Spring of 1991.

HCFA continues to use a national system shared by the ten regional HCFA offices to track complaints received from

beneficiaries enrolled in HMOs and CMPs.

R-19

Mr. Roybal: In the FY 1992 budget, new "coordinated care initiatives" are proposed. What is the Department's definition of "coordinated care"?

Secretary Sullivan: Coordinated care refers to the organized delivery of medical services provided under the direction of any of a variety of entities including, but not limited to, HMOs and Preferred Provider Organizations (PPO).

R-20

Mr. Roybal: What assurances can you give us that beneficiaries will not be at risk of higher out-of-pocket costs, poorer quality care or inadequate access?

Secretary Sullivan: We believe that coordinated care is preferable to traditional fee-for-service care because it brings coherence to the delivery of health care. It emphasizes primary and preventative health care and has the potential for providing improved care at a lower cost to both the Federal government and the beneficiary.

We are continually working to improve our oversight capability so that we can assure that high quality care is provided to Medicare beneficiaries enrolled in coordinated care plans. We do not anticipate that our new initiatives will in any way compromise beneficiaries access to quality care. In fact, we expect that these initiatives will only improve the availability of high quality coordinated care. There is nothing that we are considering as part of the initiative that would result in higher out-of-pocket costs for beneficiaries.

PREVENTIVE HEALTH SERVICES FOR OLDER PERSONS

R-21.

Mr. Roybal: You have stated that "health promotion and disease prevention are important priorities in the budget."

Please describe any demonstration projects or research the Department has conducted or has planned which pilot preventive health services and health promotion for Medicare and Medicaid beneficiaries and assess the effectiveness of including coverage for these services under Medicare and Medicaid.

Secretary Sullivan: HCFA is conducting numerous prevention/health promotion demonstrations for Medicare beneficiaries including the following: 1) At six demonstration sites, a package of experimental preventive services is offered including health risk appraisals, immunizations, clinical screening services, education and counselling services for health promotion (e.g. weight reduction, smoking cessation, stress management). Experimental services at five of the six sites began in May 1989 and continue through April 1991; the sixth was an earlier demonstration. Beneficiaries will be tracked and

evaluated for short-term and long-term health outcomes through June 1994. An interim report was submitted to Congress in July 1989. Additional reports to Congress are due in April 1993 and April 1995. 2) In ten statewide sites and ten smaller areas, influenza vaccine is being offered in a demonstration conducted jointly with the Centers for Disease control. The demonstration began in October 1988, and the Congressional mandate specified that if this benefit proves to be cost-effective after two years, influenza vaccines would automatically become covered by Medicare; if results were inconclusive, which was the case, the demonstration was to continue through October 1992. A report was submitted to Congress in October 1990 and another is due in April 1993. 3) In California, New York, and Florida, Medicare beneficiaries with severe diabetic foot disease are being offered special therapeutic shoes and inserts. The demonstration began in October 1988 and the Congressional mandate specified that if this benefit proved to be cost-effective after two years, therapeutic shoes and inserts would automatically become covered by Medicare; if results were inconclusive, which was the case, the demonstration was to continue through October 1992. A report was submitted to Congress in October 1990 and another is due in April 1993. 4) In one HMO, a demonstration has been conducted of a fall prevention program which includes a self-management education curriculum, minor home renovations and the installation of safety equipment in the home. The demonstration began in 1984 and continued through December 1987. The evaluation was completed in December 1989.

HCFA is also conducting health promotion demonstrations for Medicaid beneficiaries. Section 6407 of OBRA 1989 mandated a demonstration of Medicaid coverage to pregnant women and children not otherwise qualified to receive Medicaid benefits. Awards were made to Florida, Maine, and Michigan in September 1990. Each program includes a 6-month developmental phase, a 3-year operational period and a 3-month phase-down period. As specified by Congress, the studies will be conducted to determine the effect of these demonstrations on access to care; private insurance coverage; and cost of health care. The three sites are in the pre-operational phase of the demonstration and should be operational before the end of FY 1991. An evaluation contract is scheduled for award in June 1991. An interim report to Congress is due January 1, 1992 and a final report is due January 1, 1994. Secondly, a solicitation was mailed to State Medicaid agencies in December 1990 to announce that funds are available for demonstration projects to help improve access to early medical and substance abuse treatment services, and other relevant services which address the diverse needs of Medicaid-eligible, pregnant substance abusers and their infants. Projects will be conducted in carefully targeted communities identified by States as having demonstrated substance-abuse problems and a large number of Medicaid-eligible females of child-bearing age. The projects will have a 6-12 month developmental phase, followed by a 3-year operational phase and a 6-month phase out period. HCFA expects to make up to five awards in September 1991. An evaluation contract

is scheduled for award by June 1992.

HCFA currently has two prevention/health promotion research projects underway. The utilization, effectiveness, and cost-effectiveness of covering pneumococcal vaccine for Medicare beneficiaries is being studied. The vaccine has been covered by Medicare since July 1981.

In addition, HCFA is studying the utilization, expenditures, and effects of preventive services for California children continuously enrolled in Medicaid in 1981. Findings from the analysis of data to date show that 62 percent of the children under 15 and 45 percent of those under 5 received no preventive services under the Medicaid program in 1981. Children in semi-urban and rural areas has fewer preventive visits than did children in urban areas. The final report will be completed in 1991.

R-22

MINORITY HEALTH

Roybal: Last year the Appropriation's conferees agreed that this "nation must make a greater commitment to improving the health status of minorities in the United States and increasing their representation in the health professions." The Conferees expressed their strong support for the initiatives created by the Disadvantaged Minority Health Improvement Act of 1990 and provided \$20,000,000 of start-up funds.

With regards to the Disadvantaged Minority Health Improvement Act of 1990, can you describe in detail what budget allocations have been made for FY 1992 in the following areas: Hispanic Centers of Excellence, Grants and Scholarships, Federal Capital Contributions to Student Loan Funds, Loan Repayment for Faculty Service, Grants to States/Community-Based Organizations for Scholarships, Health Services for Residents of Public Housing and Data Collection.

Secretary Sullivan: Yes. The net amount available for these programs, after mandatory reductions to the FY 1991 appropriation, was \$19.1 million. The following chart reflects FY 1992 budget allocations for these programs, an increase of \$12.1 million, or 63 percent, over FY 1991.

Hispanic Centers of Excellence.....	\$1,464,000
Native American Centers of Excellence.....	976,000
Grants and Scholarships.....	8,295,000
Grants to States/Community Organizations for Scholarships.....	488,000
Federal Capital Contributions to Student Loan Funds.....	15,000,000
Loan Repayment for Faculty Service....	976,000
Health Services for Public Housing Residents.....	3,000,000
Data Collection.....	975,000

Total..... \$31,174,000

R-23

Mr. Roybal: The Appropriation's conferees also stated, "the Department of Health and Human Services must increase resources to minority health and training." Accordingly, the NIH, HRSA and ADAMHA are directed to develop plans that would substantially increase funding and resources in these areas.

What resources (detailed by program) within the NIH, HRSA, and ADAMHA have been allocated for minority health and training in the FY 1992 Administrations's budget proposal?

Dr. Sullivan: In total, we are requesting \$485 million for PHS programs which specifically and directly support minority health and training efforts in FY 1992. The following table reflects only the spending plans of the NIH, HRSA and ADAMHA consonant with your request.

R-24

Mr. Roybal: How much new money is the NIH, HRSA, and ADAMHA planning to direct for minority health and training for FY 1992 to the Minority Biomedical Research Support and Minority Access Research Center programs?

Dr. Sullivan: The FY 1992 NIH and ADAMHA budget requests include \$62.7 million for these programs, compared to \$58.9 million in FY 1991. This is an increase of \$3.8 million, or 6.5 percent, over FY 1991 program levels. The Minority Biomedical Research Support and Minority Access Research Career programs are not supported through HRSA.

R-25

Mr. Roybal: How much new money is the NIH, HRSA, and ADAMHA planning to direct to the Health Career Opportunity Program for minority health and training for FY 1992?

Dr. Sullivan: The FY 1992 HRSA budget request includes \$26.3 million for the Health Careers Opportunity Program. This is \$1.6 million, or 6.5 percent, more than in FY 1991. This program is not supported through NIH and ADAMHA.

R-26

Mr. Roybal: How much new money is the NIH, HRSA, and ADAMHA planning to direct for minority health and training for FY 1992 to the Office of Minority Health?

Dr. Sullivan: We have no plans to redirect funds from these programs to the Office of Minority Health (OMH). The OMH receives a direct appropriation through the Office of the Assistant Secretary for Health. For FY 1992, we are requesting \$20 million, an increase of \$1 million (+5 percent) over the FY 1991 level, and \$12 million (+150 percent) over the FY 1990 level. The role of the OMH is to formulate and develop minority health policy, coordinate Department program efforts, and provide public and private sector outreach. While the OMH has some grant making authority, we prefer to preserve its policy, leadership, liaison, and coordinative role.

R-27

Mr. Roybal: NIH, HRSA, and ADAMHA were directed by the appropriation's committees to develop and submit their plans, within six months, to substantially increase funding and resources in the aforementioned areas. Can you send me a copy of these plans pursuant to the Conference Committee Report by May 1991?

Dr. Sullivan: These agencies are currently completing their final draft reports. We expect to transmit them to the Congress by May 1991.

R-28

BIOMEDICAL RESEARCH

Mr. Roybal: You have outlined in your Department's budget an emphasis on strengthening biomedical and behavioral research at the National Institutes of Health. You also emphasize that this research will benefit all Americans. How are the Hispanic populations of the United States benefiting from your proposed biomedical research agenda?

Dr. Sullivan: Both Hispanic and non-Hispanic populations will benefit from proposed biomedical research which will examine disease processes which affect individual health status. For instance, similar to other minority populations, diabetes and AIDS are known to disproportionately affect the Hispanic population. While biomedical research in these areas is not necessarily targeted to the Hispanic community, we expect this research to have a significant impact on improving the health status of Hispanic Americans.

Examples of specific efforts to improve biomedical and behavioral information on the Hispanic population include:

- o a clinical trial on maternal hematocrit levels to examine unexplained differences in the high risk of preterm birth;
- o a clinical trial on a behavioral program designed to reduce adolescents' unsafe sexual behavior;
- o the National Institute on Drug Abuse (NIDA) collaborating with the National Center for Health Statistics (NCHS) to improve data sets on drug use by including questions on the Hispanic Health and Nutrition Examination Survey (HHANES); and
- o ADAMHA support of two research centers which study the causes and consequences of psychiatric disorders among Hispanic populations -- the Center for Cross-Cultural Research at Galveston, Texas and the Hispanic Research Center at Fordham University, New York.

r29

Mr. Roybal: What efforts is the Department making to involve and recruit Hispanic investigators and scientists (biomedical and behavioral)?

Dr. Sullivan: Currently, the Minority Institutions Research Development Program is providing funds for institutional development and faculty research support to one predominately Hispanic university -- the University of Texas at El Paso. Also, the Research Centers at Minority Institutions program is providing funds to institutions with high Hispanic enrollment -- the University of Puerto Rico, Rio Piedras and Medical Sciences Campuses, the Ponce Medical School, Universidad Central Del Caribe, and the Charles R. Drew Postgraduate Medical College. However, we expect all Department biomedical and behavioral training support programs to involve and recruit Hispanic investigators and scientists.

Of the 59 institutions currently receiving support under the Minority Access to Research Careers (MARC) program, 16 are predominantly Hispanic or have significant numbers of Hispanic students and will receive \$2.4 million in FY 1991. This program mentors students at the undergraduate level in order to compete successfully at the graduate and Ph.D. level. Also, \$8.0 million of support is available this year through the Minority Biomedical Research Support (MBRS) program which awards grants to educational institutions in order to support research by faculty members, strengthen the institution's biomedical research capabilities, and provide opportunities for students to work as part of a research team. The institutions supported by these programs include:

- o California State University, Long Beach
- o California State University, Los Angeles
- o California State University, Northridge
- o Catholic University of Puerto Rico
- o Charles R. Drew Postgraduate Medical School
- o Humacao University College, Puerto Rico
- o New Mexico State University
- o San Diego State University
- o San Jose State University
- o Saint Mary's University of San Antonio
- o Texas Southern University
- o University of California, Santa Cruz
- o University of New Mexico, Albuquerque
- o University of Puerto Rico, Rio Piedras
- o University of Texas, El Paso
- o University of Texas, San Antonio
- o California State University, Fullerton
- o Cayey University College
- o College of Santa Fe
- o Inter American University of Puerto Rico
- o Los Angeles Community College District
- o New Mexico Highlands University
- o Pan American University
- o St. Mary's University

- o Texas Agricultural and Industrial University
- o University of Puerto Rico, Medical Sciences
- o University of Southern Colorado

In addition, we are requesting \$15 million for new extramural construction program for minority institutions in FY 1992 to improve academic science facilities so researchers at minority institutions may be better able to compete for NIH research grants.

HUMAN GENOME

R-30

Mr. Roybal: The number one breakthrough in all of science will come in the 21st century in regards to the Human Genome Project. In essence we will have the understanding of the molecular origin of disease and thereby be able to manipulate disease causation and cure.

Knowing that the Hispanic population is the fastest growing population in the U.S., and will probably be the largest group in the next century, what consideration has been given to include Hispanics in this resounding breakthrough in science?

Secretary Sullivan: The purpose of the Human Genome Project is to map and sequence the human genes to provide a greater understanding of human biology in general. The end product of the Genome Project will not specific to any one race or sex, but rather common to humankind. Once this tool is available scientists will be able to more easily study genetic based diseases, some of which are prevalent only in certain races, or ethnic groups.

NURSING HOME REFORM

R-31.

Mr. Roybal: During the past week, some very troubling events have developed over the implementation of the nursing home reform law in California.

As I understand it, the State of California has refused to conduct the same nursing home surveys which all 49 other states are now performing. That State has taken this position on the premise that its compliance with the law will result in an additional cost to the State of somewhere between \$400 million and \$500 million.

Until last week, the Health Care Financing Administration had been adamant in requiring that California obey the law. On March 11, 1991, however, HCFA signed a so-called agreement with the State of California that certainly gives the appearance that the agency is now backing away from its very strong enforcement position. This arrangement is of particular concern given the timing of the agreement: it comes on the heels of a letter from Governor Wilson to President Bush in which the Governor requests that the President "help in resolving a disagreement between the

Health Care Financing Administration and the State of California"

Let me first ask you: Is the Department now suggesting that its interpretative guidelines are inappropriate?

Secretary Sullivan: No. We have merely agreed to review those guidelines to ensure that they are consistent with their intent and that they cannot be read as imposing requirements on nursing facilities that are not already imposed by the statute and regulations.

R-32.

Mr. Roybal: Is the Department now suggesting that its position regarding the implementation and the enforcement of the nursing home reform law in California has been wrong?

Secretary Sullivan: No. The position we are taking now is completely consistent with the position we have taken with California and other states from the beginning: (1) Requirements on facilities are specified in the statute and regulations and (2) state survey agencies are required to use the HCFA protocol in conducting surveys to determine if facilities are meeting those requirements.

R-33.

Mr. Roybal: If so, why have you been battling with California for well over a year now?

Secretary Sullivan: Until our recent agreement, California refused to accept our explanations of what they were required to do and what the impact of the survey protocol is on state agencies. The state has now agreed to conduct surveys in accordance with the HCFA protocol.

R-34.

Mr. Roybal: After HCFA and California signed this agreement on March 11, 1991, Governor Wilson put out a press release in which he said -- and I quote from the release itself -- "the White House has been very helpful in finding a way to resolve the problems raised by California."

What do you think Governor Wilson meant by this statement?

Secretary Sullivan: I do not believe it is appropriate for the Department to speculate on what Governor Wilson meant.

R-35.

Mr. Roybal: Was the White House helpful?

Secretary Sullivan: To the best of my knowledge the White House did not play any role in the agreement.

R-36.

Mr. Roybal: Did you receive any communication or contact -- either written or oral -- from the White House about this issue?

Secretary Sullivan: No.

R-37.

Mr. Roybal: Did Dr. Wilensky?

Secretary Sullivan: Staff in the Office of Management and Budget phoned Dr. Wilensky to learn more about the dispute with the State of California. Dr. Wilensky explained the background of this dispute and position that HCFA was taking. These communications were oral.

R-38.

Mr. Roybal: Did any of your assistants or any of Dr. Wilensky's assistants?

Secretary Sullivan: Staff in the White House phoned HCFA staff to learn more about the dispute with the State of California. Staff explained the background of this dispute and the position that was being taken. The Secretary's General Counsel provided information to White House Counsel about the legal issues of the dispute.

R-39.

Mr. Roybal: If so, please provide all information and documentation regarding these contacts for the record.

Secretary Sullivan: These communications were oral, all by telephone.

R-40.

Mr. Roybal: The tone of the agreement signed by HCFA and the State of California seems to indicate that HCFA will, indeed, make changes in its interpretative guidelines. That agreement gives the interested parties 30 days to "review and revise" those guidelines. With only three weeks remaining before the agreement's deadline, you must have a good idea about what changes are being contemplated.

Please describe those proposed changes to us.

Secretary Sullivan: Revised interpretive guidelines will be sent to all states and interested parties very soon outlining the changes we will be making. A copy will be provided to you at that time.

R-41.

Mr. Roybal: Please describe the Department's justification for those changes.

Secretary Sullivan: Each proposed change is designed to make the guidelines more consistent with the original intent of the HCFA survey protocol: To provide guidance to surveyors in the conduct of surveys of facilities participating in Medicare and Medicaid, to provide guidelines, suggestions, interpretations, check lists and other tools for surveyors to use. The changes will make clear that the guidelines do not impose conditions and requirements on facilities that are not already contained or inherent in the statute and regulations, thus eliminating California's argument that the guidelines impose additional costs on facilities, a result that was never intended.

R-42.

USER FEES FOR SURVEY AND CERTIFICATION

Mr. Roybal: Once again, the Bush Administration has proposed that user fees be imposed to finance the survey and certification process for nursing homes as well as other health facilities. That proposal was specifically rejected by the Congress last year and I suspect it will be turned down flatly again this year.

If the Congress does not authorize user fees, what is the Department's contingency plan for assuring that the Nation's nursing homes meet OBRA 87's health and safety requirements?

Secretary Sullivan: Medicare and Medicaid have historically subsidized the survey and certification costs of all payers. These costs should be a regular cost of doing business, to be equitably allocated among all of a provider's lines of business. Therefore, we believe that user fees are justified, and that our proposal should be enacted. Additionally, the user fee proposal builds on the precedent established by Congress in the Clinical Laboratory Improvement Act of 1988 (CLIA 88).

HCFA is initiating discussions with the authorizing committees on this matter. We are hopeful that the merits of survey and certification user fees will outweigh any opposition to our proposal. We are sensitive to the concerns that are raised by proposals that cross jurisdictional boundaries. HCFA will do what it can to help address these jurisdictional concerns.

R-43.

Mr. Roybal: Is the Administration's Medicaid and Medicare budget requests — short of the dollars assumed under the user fee concept — enough to get the job done?

Secretary Sullivan: Our budget request for survey and certification activities assumes ultimate Congressional approval of our survey and certification user fee proposal. If, in fact, the Congress decides not to approve this funding proposal, HCFA must then fall back on existing funding authority and request total appropriations of over \$286 million for the Medicare and the Medicaid survey and certification activities as follows:

(Dollars in Millions)

Medicare

Trust Fund Transfer for Direct

Survey Activities \$147.5

Budget Authority for Contract

Support 12.5

Medicaid

Budget Authority 91.5

Administrative Costs

Trust Fund Transfer (Medicare) 27.0

Budget Authority (Medicaid) 7.9

TOTAL FY 92 (Current Law) Requirements \$286.4

ALZHEIMER'S DISEASE MEDICAL REMEDIES

R-44

Mr. Roybal: As you know, I am very concerned about Alzheimer's disease, and about the need to develop medical remedies for this debilitating illness. It is my understanding that last Friday the Food and Drug Administration decided not to recommend approval of "TACRINE", a drug specifically developed for the treatment of Alzheimer's disease. Do you view the development of medical remedies for Alzheimer's disease as a priority for the Department?

Secretary Sullivan: Alzheimer's disease afflicts over 4 million older Americans and costs this Nation billions of dollars in health costs and lost productivity. Thus, developing treatments for Alzheimer's disease is of course a priority for the Department.

In total, HHS will spend over \$240 million in 1992 on Alzheimer's disease research. Several agencies of the Public Health Service, including the National Institute on Aging and the National Institute on Mental Health, devote large portions of their resources to studies designed to acquire greater knowledge about the causes and dynamics of the disease as well as to develop therapies for those already afflicted. Each year we learn more and more about the disease and how to treat it. I am confident our progress will continue.

R-45

Mr. Roybal: Do you anticipate the development of such medical remedies in the near future?

Secretary Sullivan: Given our continued progress, I am optimistic that an effective therapy will emerge. One such potential therapy is the experimental drug tetrahydroaminoacridine (THA), which we hope will control memory loss in patients with Alzheimer's disease. A 300 patient clinical trial was recently completed on THA and the study results await peer review and publication. In addition, researchers at the National Institute on Mental Health (NIMH) are searching for Alzheimer's disease treatments by combining existing neuro-therapeutic agents. One school of thought holds that combination treatments may be the dominant therapeutic approach for Alzheimer's disease in the 1990s.

AIDS RISK PREVALENCE SURVEY

R-46

Mr. Roybal: We were delighted to learn that the Administration included \$3 million to launch the full scale version of this survey, yet the feasibility phase has been held up in your office for some time. Can you please explain why completion of this project has been held up in your office?

Secretary Sullivan: Over the last several years we have received mixed signals from the Congress with regard to the predecessor of this survey, the National Survey of Health and Sexual Behavior. In FY 1990, the House Appropriations Committee included report language with its FY 1991 Appropriations bill which stated that "This does not appear to be an appropriate use of government funds; if such a survey is necessary, it should be supported with non-governmental funds. The Public Health Service is directed not to proceed with this survey." Reacting to this, we neither requested, nor did we receive, any funds for such a project in FY 1991. We did, however, revise our plan and reorient our approach to focus more closely on AIDS, and the risk of sexual transmission of AIDS. This revised survey has become the Study of Health and AIDS Risk Prevalence (SHARP). Based on the results of the Dallas pre-test of our seroprevalence survey, we believe that we can proceed with the full implementation of this survey without further investment in feasibility activities.

R-47

Mr. Roybal: When do you plan to direct NIH to proceed with this effort?

Secretary Sullivan: Our request for FY 1992 includes \$3 million to begin the implementation of the survey. Pending clear Congressional support, we will be able to begin the initial work on the large scale survey. This will allow us to fully develop the survey instrument, begin training interviewers, and start the preliminary recruitment and sampling of subjects.

AIDS DENTAL REIMBURSEMENT

R-48

Mr. Roybal: AIDS is a significant health problem, and some of the first signs of the disease occur in the mouth. It is important that dental students learn how to recognize the disease and to care for AIDS patients. What is the Department doing to train dentists to take care of these patients?

Secretary Sullivan: We are concerned with this problem and our budget includes \$17 million to support a national network of 16 AIDS Education and Training Centers (ETCs). These centers provide training to primary and dental care providers and develop model educational programs for training these providers. offer policies.

STATE LEGALIZATION IMMIGRATION ASSISTANCE GRANTS

R49

Mr. Roybal: I commend you for your interest in reducing infant mortality and in increasing access to health care for minorities and underserved populations. I am therefore puzzled by your Department's support to rescind SLIAG funds because so much of those funds are used to pay for prenatal and other health services provided to a population with tremendous health care needs. To date, how much SLIAG funds have been used to reimburse state and local costs of public health services, Medicaid and indigent health services provided to legalized aliens?

Secretary Sullivan: Costs for public health services for FY 1988 - 1991 are expected to total \$134 million. State and local costs for indigent health care and primary health care programs are estimated to be 93 percent of the amount reported for public assistance minus the amount reported for Medicaid. This amount is \$511 million.

States have not yet reported all Medicaid costs; the data provided are therefore underestimates by an unknown percentage. Partial reported data indicate that State Medicaid costs are \$201 million. In addition, it is estimated that Medicaid costs through FY 1991 will increase by \$109 million. This estimate is based upon indications from States that \$90 million in Medicaid costs will soon be reported.

In general, SLIAG funds do not increase the availability of or access to health care for minorities and underserved populations. Rather, SLIAG merely reimburses the State treasury for costs of ongoing programs which can be attributed to services provided to IRCA-legalized aliens. In California's case, SLIAG has merely replaced State funds already being spent on health services. As a result, SLIAG does not provide services - rather it subsidizes State budgets.

COMMUNITY SERVICE BLOCK GRANTS

r50

Mr. Roybal: It is my understanding that the Administration's intention is to eliminate the Community Service Block Grants (CSBG), which fund programs designed to combat poverty at the local level and have Social Service Block Grants pick up the CSBG programs. The FY 92 budget, however, does not provide an increase in funding for these additional programs. How are the CSBG activities to be funded if there is no increase in the budget?

Secretary Sullivan: The Community Service Block Grant (CSBG) program was initiated to assist in establishing an infrastructure for improving services to low-income individuals and families. Since that time, that infrastructure, comprised primarily of local Community Action Agencies (CAAs), have become quite successful in obtaining funding from a variety of sources. In fact CSBG now represents only about 10% of the funding for most of these agencies. Because of this, and the limitations on the Federal

budget for domestic spending, we have recommended the elimination of the CSBG in FY 92.

R 51

Mr. Roybal: Community Service Block Grants focus their activities on antipoverty programs. By eliminating these programs, many low income children, families and elderly would suffer. What alternatives is the Department offering to these individuals?

R-51

Secretary Sullivan: Community Service Block Grants provide only a small fraction of the funding for anti-poverty programs on the State and local level. In addition, we have expanded Federal programs aimed at America's families in need. Specifically, we have requested increased resources for Head Start and will have substantial outlays for child care when the Child Care and Development Block Grants become available.

SOCIAL SECURITY ADMINISTRATION

R-52.

Mr. Roybal: As you know, the 1-800 telephone number instituted by the Social Security Administration to answer inquiries from the public has had a history of problems since it was initiated in 1989. Among these problems have been wrong responses to questions, no response at all, or simply a busy signal. What is the current status of SSA 1-800 number?

Secretary Sullivan: The "800" number has been a huge success with the public. They have demonstrated a strong preference for conducting business with SSA over the telephone. In 1990, SSA served about 53 million clients through the 800 number. Although busy rates have remained above the targeted levels, the total number of clients SSA serves continues to increase. SSA expects to serve about 68 million clients in FY 1992. While we believe busy rates are an important service indicator for the "800" number, gauging the amount of service provided is equally important.

The current budget includes an increase in estimated workyears for the "800" number to 4,132 workyears in FY 1991 and 4,395 workyears in FY 1992 compared with about 3,900 workyears estimated in the FY 1991 President's budget. These increased funding levels are aimed at providing the staffing necessary to handle projected increases in the volume of calls to the "800" number in both FY 1991 and FY 1992. We do not anticipate that SSA will be able to improve busy rates in FY 1991 at the current resource level.

In order to further address service concerns, we will retain the same managerial flexibility in FY 1991 and FY 1992 which we have used in FY 1990 to improve service. An example of that flexible response is trained benefit authorizers in SSA's processing centers helping to handle calls at the "800" number when calls reach a peak. Also, part-time teleservice representatives (TSR) have been offered full time employment,

additional TSR's have been hired, and overtime has been offered to TSR's.

Mr. Roybal: When will SSA resume printing the telephone numbers of local SSA offices in the local phone book?

Secretary Sullivan: In January 1990 SSA directed that "800" number teleservice representatives provide local telephone numbers on request. The Omnibus Budget Reconciliation Act of 1990 requires that local telephone numbers and addresses, as they existed on September 30, 1989, are to be published in future directory publications. Completion of this activity is dependent on phone book publishing schedules. We will complete the publication of the local numbers as soon as is possible.

OLDER AMERICANS ACT

Mr. Roybal: Individuals who administer the Older Americans Act on the local and State levels have made me aware that the Administration on Aging (AoA) has great difficulty delivering technical assistance to them since it has little control over staffing and budget. Infact, they are recommending that the Commissioner on Aging be elevated to the rank of Assistant Secretary at HHS to alleviate this problem. Would you support such a recommendation or make any other changes to allow the Commissioner on Aging to have her own personnel and budget?

Secretary Sullivan: I want to assure you that, although the Administration on Aging (AoA) receives logistical and other support from the Office of Human Development Services (OHDS), the Commissioner on Aging does report directly to me. The Commissioner on Aging was a full participant throughout the Department's and the Administration's FY 1992 budget formulation process, and our FY 1992 request for staffing resources for AoA within the OHDS budget reflects input from AoA at all levels. I would also add, that the Commissioner on Aging is the only Administration head receiving management support through the Human Development Services appropriation that has complete discretion over all staffing decisions for the agency.

ELDER ABUSE IN BOARD AND CARE HOMES

Mr. Roybal: According to recent estimates by my subcommittee on Health and Long-Term Care, over a million elderly and disabled americans live in some 68,000 licensed and unlicensed board and care homes today. One of the most disturbing phenomena in these homes is the overmedication of residents. Residents are administered multiple prescription drugs in order to keep them quiet and reduce the amount of attention they require. What is the Department doing to investigate problems in board and care homes, which at present are not regulated with any uniformity at

the state level are regulated ineffectively at the federal level?

Secretary Sullivan: We recognize that board and care is an issue that will grow in importance during the 1990's. Much like nursing homes in the 1970's, there are concerns about the extent and quality of care. Yet, there is almost no reliable information on the number of licensed and unlicensed board and care homes, the number and characteristics of residents, their care needs, the background and qualifications of owners and operators, and the quality of care provided. Most importantly from my perspective, we have no information on how to effectively regulate these homes to ensure that residents are appropriately protected from abuse.

I think it would be a big mistake to assume based on anecdotal evidence that the Federal Government can do a better job in assuring board and care quality than is now being done by the states. I believe the most appropriate role my agency can now play is to collect some systematic information on how board and care homes actually operate, what is wrong and what types of incentives, assistance and regulation seem to work best to support this important component of the long-term care system.

To implement this role, the Department has begun systematically to build a base of information about board and care homes that can support the analysis of proposed legislative and policy options.

Some of the components of this information base include:

- (1) A study being done by the Research Triangle Institute to examine how states now regulate board and care homes and the impact of different regulatory strategies on the quality of these homes. Carried out under the direction of the Office of the Assistant Secretary for Planning and Evaluation (ASPE), the study is in response to the recommendations of the February 1989 GAO report on board and care homes.

Visits will be made to about 600 board and care homes in ten different states and interviews will be conducted with residents and operators to examine factors associated with differences in quality, with particular emphasis on the effect of regulation. One of the many issues that will be examined is the administration of drugs including the use of psychotropic medicines. We intend to coordinate this aspect of the study with the shorter term effort now being carried out by the GAO to look at the use of drugs in board and care homes. A final evaluation report is expected by September 1992.

- (2) ASPE and the National Center for Health Statistics have also agreed to include licensed board and care homes in the 1991 update of the National Health Provider Inventory (NHPI). The NHPI will yield basic information about licensed board and care homes and serve as a sampling frame for more specialized studies.
- (3) The Administration on Aging (AoA) administers funding for state-run ombudsman programs, which were expanded in 1981 to include board and care homes as well as nursing homes. In

response to the Older American Act Amendments of 1987, AoA studied the impact of these ombudsman programs on board and care residents. The report concluded that ombudsmen are involved with board and care at both the service delivery (e.g. complaint investigations) and systems development (e.g. proposed legislation and regulation) levels. The major needs are more ombudsmen staff and more training and technical assistance for the ombudsman program.

- (4) The Office of Inspector General (OIG) issued a report (March 1990) which assessed the comprehensiveness of existing state board and care regulations and the extent to which regulations were enforced. This study found that state standards adequately covered basic safety and service requirements; however weaknesses were identified in several areas such as the level of care needs for residents, dealing with unlicensed facilities and provider coordination. Deficiencies in state enforcement activities were also found.

In response to the OIG report, the Department plans to establish an ongoing board and care task force, consisting of representatives from relevant operating components (HCFA, OHDS, AoA, PHS and others) and chaired by ASPE. As presently conceived, the role of the task force will be to: (a) determine what is and is not known about board and care; (b) exchange information among task force members, state regulatory agencies, national residential care associations and others as appropriate; (c) propose and oversee a board and care research agenda; and (d) examine policy options for addressing concerns about board and care.

- (5) Under 1990 OBRA, a new capped entitlement program has been established under Medicaid, permitting states to provide home and community-based services to persons with severe disabilities. DHHS is required to establish minimum quality standards for participating providers of care, including board and care homes, and to assure compliance with these standards under appropriate survey and certification procedures. The Health Care Financing Administration is currently developing the implementing regulations.

R-56.

Mr. Roybal: I would like to call upon the Institute of Medicine to conduct a national study, as it did with nursing homes, to devise comprehensive federal regulations for board and care homes. Would you support this effort?

Secretary Sullivan: I would not support an IOM study at this time. My Agency will be investing about \$750,000 to evaluate how state regulation affects board and care quality. We will be examining states with vigorous and aggressive regulation and states with less stringent standards and enforcement. This study is being carried out by the leading researchers in this area and is supported by an extensive advisory team made up highly knowledgeable practitioners, state and local officials, research methodologists, and Federal policymakers. I think this work should be completed and its recommendations considered in developing any new Federal regulatory strategy.

NATIONAL CENTER FOR HEALTH STATISTICS

Mr. Roybal: How would you assess the capacity of DHHS' existing programs to provide national statistics for monitoring the Nation's health and planning and evaluating national health programs?

Secretary Sullivan: Our FY 1992 request for the NCHS of \$85.2 million, a 21 percent over the previous year, demonstrates our commitment to providing quality statistical information about our Nation's health. More than one-fourth of the 1990 health objectives for the Nation could not be measured because data were not available; the FY 1992 budget will help in improving our measurement of the Year 2000 objectives.

R-58 Mr. Roybal: What kinds of national health statistics are needed in order to properly address the nation's most outstanding problems?

Secretary Sullivan: Each of the priority areas identified in our Year 2000 objectives will require special emphasis in the nation's health statistical system. Areas of emphasis include infant mortality, nutrition, and HIV. We will be working on improving surveillance and data systems. Health problems of minorities and other vulnerable population groups will also require additional efforts to improve minority statistics through national surveys.

R-59 Mr. Roybal: What is DHHS doing to assure that the nation will have high quality and timely national health statistics?

Secretary Sullivan: Our FY 1992 request for the NCHS of \$85.2 million, a 21 percent increase over the previous year, demonstrates our commitment to obtaining high quality on timely national health statistics. This will provide added data collection capacity and enhanced automation and analytical approaches to strengthen our excellence in infectious and chronic disease control and occupational and environmental health.

GUARDIANSHIP

R-60. Mr. Roybal: The guardianship system in this country is in serious need of reform. As previously constituted, this system wrongly appoints guardians, fails to perform oversight of guardianship arrangements, and appoints convicted felons as guardians. Obviously, the existing guardianship system is in need of reform. What do you suggest to clean up the system?

Secretary Sullivan: We are very concerned with ensuring that our most vulnerable citizens are protected and that our policies provide appropriate safeguards. We share your concern that minors who have had the misfortune to be separated from their parents be provided the best possible protection and guidance that our legal system will allow. Although much of the Department's resources are devoted to strengthening and keeping families together, we also seek to ensure, whenever possible, that children who cannot be cared for by their parents receive the best available substitute care and representation.

ELDER ABUSE TASK FORCE

Mr. Roybal : You have established a task force on Elder Abuse, which is expected to release to you its draft soon. Don't you think a new federal campaign is needed to combat this problem, which afflicts an estimated 1.5 million Americans annually?

Secretary Sullivan: I recognize there is increased concern about the problem of elder abuse and I certainly share that concern. This is why I have set up a special task force to make recommendations to me about what the Department should do to address this problem. At this time, the task force is considering a two-pronged strategy which would: (1) improve our basic knowledge about the extent of elder abuse, who is affected and the underlying causes; as well as (2) provide assistance to the states and localities on the front lines who are directly responsible for the prevention, resolution and treatment of elder abuse. I look forward to sharing with you my elder abuse plan in the near future.

LONG TERM CARE

Mr. Roybal: In his January State of the Union message, President Bush remarked that "good health care is every American's right." I know that, to date, he has emphasized preventative measures, such as smoking cessation and exercise, as a way of ensuring good health for Americans. What about the millions of Americans for whom preventative measures are of no use--those in need of long-term care for cancer, Alzheimer's, stroke, etc. Doesn't the government owe these people meaningful programs, too?

Secretary Sullivan: We must take a comprehensive approach to long-term care, which is one of the most critical concerns of our elderly citizens. One part of the answer lies in the area of financing. The rapid growth in long-term care expenditures cannot be handled by the public sector alone. We need a balance among out-of-pocket expenditures, long-term care insurance, other private financing mechanisms and public programs. Only in this way can we assure that the long-term care needs of cancer patients, Alzheimer's victims and others will be met appropriately.

Under my direction, the Deputy Secretary with the Department's Policy Council is examining all aspects of long-term care financing. Her report will provide a valuable perspective not only for Departmental policymakers but for society as a whole, as we grapple with this vital issue.

However, I absolutely agree that prevention strategies are an important dimension of long-term care policy. By not smoking, drinking moderately or not at all, eating properly and exercising, Americans of all ages will improve their health, extend their lives and lower the risk of needing acute and long-term care. As Secretary, I have emphasized both the financing and prevention aspects of our long-term care system. These are not mutually exclusive. Both are critical.

R-63

Mr. Roybal: Private long-term care insurance is sometimes mentioned as a possible remedy to the current crisis in long-term care. Yet, a recent GAO study showed that less than 50% of Americans can afford a long-term care policy. Shouldn't there be a federal alternative to cover the 50% with no coverage?

Secretary Sullivan: We agree that not all people are good candidates for private long-term care insurance. People who are very old or who are already disabled, and people with few or no assets or low incomes are not going to be able to purchase insurance. However, the Medicaid program does ensure access to nursing home care for all Americans when their resources are inadequate to cover the cost of their care. So there is a Federal alternative, although one that requires people to first spend a significant portion of their income and assets paying for care before they are eligible. My review of Federal long-term care policies includes an examination of the impact of Medicaid spend down provisions on people who need long-term care.

I would also add that the longer people wait before they begin to plan for their future long-term care needs, the less "affordable" financial protection from high long-term care costs becomes. The more individuals start participating in risk pooling, and the earlier they start, the more affordable long-term care will be to a greater percentage of the elderly. I think we all need to be more aware of our risk of needing long-term care and to take more responsibility for planning for that risk much earlier in our adult lives.

U.S. HEALTH SYSTEM REFORM

R-64

Mr. Roybal: Mr. Secretary, our infant mortality rate is higher than Singapore's, our life expectancy is lower than Cuba's, as many as 1 million of our citizens become impoverished each year trying to meet the costs associated with long-term illnesses such as Alzheimer's Disease and Cancer. We spend a higher percentage of our GNP--11%--on health than any other nation. In light of these distressing facts, don't you think the time is right for sweeping changes in the U.S. health system?

Secretary Sullivan: The problems our nation faces with infant mortality and shortened life expectancy for teenagers and young adults often have as much if not more to do with issues of health promotion and preventive public health measures than with the adequacy of our health care financing and service delivery system. This is why I have devoted so much of my time and energy as Secretary to campaigning against smoking, against drugs, against alcohol abuse and drunk driving, against violence, and in favor of healthful nutrition and exercise, childhood immunizations and education about how to stop the spread of HIV infection and other communicable diseases. I am certainly deeply concerned about whether we are getting our money's worth from the tremendous amount of money we are investing in our health care system. As you are aware I am now conducting a study to examine the problems of our health care financing system and proposed solutions to these problems. So far it is not clear to me that any of the so-called "sweeping changes" will produce the kinds of improvements that we all wish for at a price that we are willing to pay.

NATIONAL MARROW DONOR PROGRAM

Y-1

Mr. Young: You will recall that we had a very good discussion last year about the success of the National Marrow Donor Program and about the ongoing need to add donors to the national registry. I am pleased to report that in the 12 months since our last meeting, the National Registry has grown more than three fold as we have added almost 200,000 new donors. Most importantly, in the 3 1/2 years since the program became operational, we have completed 600 transplants through the registry, 300 in just the past 12 months, and we are now successfully finding matched donors at the rate of 30 per month.

The program is working well, recruitment is more successful than even our most optimistic predictions, in large part because of the support of this Committee for federal funding of donor recruitment activities. The one area where we still need to do a better job, however, is minority recruitment. Less than 10 percent of the registered volunteers represent minority groups. Although low, we have four times more minority donors in the registry now than we did 12 months ago. Among these minority groups, we have an especially difficult time recruiting in the black community. Since last March, we have increased the number of black Americans in the registry by almost 4,600, from 2,718 last year to 7,275 currently, but this is the slowest rate of growth for any of the major minority groups.

Mr. Secretary, I would be especially interested in your thoughts about the National Marrow Donor Program and about ways in which we can educate and encourage more black Americans to volunteer for this life saving program.

Secretary Sullivan: While I am quite pleased in general with the progress that the National Marrow Donor Program has made in the past year, under the guidance of the National Heart Lung and Blood Institute, I too am quite concerned about the low representation of Afro-Americans among the pool of volunteer members of the National Registry.

There are several steps which we can take to recruit more minority members into the National Registry. A recruitment activity which should pay significant dividends is the training of staff at marrow donor centers in communities with large minority populations. These workshops not only allow us to educate the medical community at large but also allow us to become more knowledgeable ourselves about effective recruitment tactics. As a result of 13 workshops conducted in 1990, the National Marrow Donor Program is developing a mass media campaign including a recruitment video, volunteer orientation kit, posters and news releases, and radio and television public service announcements to be targeted to minority populations, especially blacks and Hispanics.

CHILDHOOD IMMUNIZATION

Y-2

Mr. Young: Mr. Secretary, you have made some very important statements today about the quality of life for children not only in the United States but throughout the world and I want to applaud you for the vigor with which you have pursued the infant mortality initiative. With regard to the care of our children, I have been greatly concerned these past two years by the sharp increase in the outbreak of a number of childhood diseases such as measles, rubella and whooping cough. These are diseases which are preventable through immunization, but because the cost of these vaccines has risen so dramatically over the past few years, fewer children receive their vaccines on schedule. Last year alone, 25,000 measles cases, resulting in more than 70 deaths, were reported, the highest level in more than 12 years. The number of rubella cases doubled in 1989 and tripled last year. The incidence of whooping cough, which fell to an all-time low 1,248 in 1981, exceeded 4,000 cases last year. These are preventable diseases. Mr. Secretary, how do you believe we can reverse these trends and make these vaccines more available to preschoolers throughout our nation?

Secretary Sullivan: As a Nation, we are doing an excellent job of getting our 5-year old children, as they begin to enter school, fully immunized. Where we are having problems are with the younger children, especially 2-year old children.

Our FY 1992 budget contains several areas of emphasis to address this problem with younger children. An additional \$8.7 million is requested to investigate and evaluate the potential effectiveness of linking continued participation in low-income assistance programs - WIC, Medicaid, AFDC - with documented immunization of young children. A \$20 million incentive grants to States program is being established to increase immunization levels of Medicaid eligible 2-year old children. Finally, we requested \$6 million to assist State and local health departments identify and remove administrative barriers in vaccine delivery.

As to your comment that the dramatic price increases for vaccines we experienced in the 1980's may be the cause of the lower rates of immunization, we cannot be certain that price is a key reason. The CDC purchases over 20 million doses annually of vaccine for low-income children. Additionally, the Medicaid program finances the cost of immunization for the estimated 14 million eligible children under the age of 18. This substantial financial assistance commitment toward immunization is there for all low-income families seeking immunization services for their children.

Y-3

Mr. Young: Mr. Secretary, one of the ways in which we are looking to correct this problem not only domestically but throughout the world is through the development of a single dose children's vaccine, that would combine vaccines so that children would be able to receive greater immunization protection in fewer trips to doctors' offices and clinics. I want to applaud you for your commitment last fall to UNICEF to enhance the Administration's commitment to this program. What is the current status of the children's vaccine initiative and what are its major goals and its timetable for development?

Secretary Sullivan: As a result of last year's "Summit for Children", there has been expanded interest throughout the world to work on the Children's Vaccine Initiative. I must report that a group of domestic and international vaccine experts, that I requested the PHS organize, concluded that the feasibility for a single-dose multi-antigen preparation which would be heat-stable, given at birth, and durable throughout life is unlikely for technical reasons. However, this goal of a single-dose vaccine has resulted in a concerted effort directed toward this end, and we believe will result in speedier development of more useful vaccine preparations.

MEDICARE CONTRACTOR FUNDING

Y-4.

Mr. Young: Mr. Secretary, I want to express concern about one item in your budget request that could cause tremendous hardship on older Americans not only in Florida, but throughout our nation. The request for Medicare contractors would provide almost level funding. At the same time, the number of Medicare claims processed in Florida will increase from 41.6 to 47.4 million between Fiscal Years 1991 and 1992. While the request for an 11 percent increase in funding for claims processing will almost keep pace with this projected 14 percent increase, your budget request cuts in half the funds allotted for beneficiary and provider services and provides a small reduction in funding for payment safeguards. The contractors estimate that these reductions mean that fewer than 9 million of the more than 30 million beneficiary and provider inquiries will be able to be answered and that only 3 million of the projected 10 million beneficiary and provider disputes will be resolved. In preparing your budget request for the Office of Management and Budget and in your final submission of your request to Congress, did you take these projections into consideration?

Secretary Sullivan: Yes, we carefully considered these projections in our budget requests to both the Office of Management and Budget and to the Congress. However, in FY 1992 we are facing grave constraints on our domestic discretionary budget. We must maintain basic standards of claims processing efficiency and we must spend money on payment safeguards in order to maintain trust fund integrity. The remaining funds must be allocated among other, important services. HCFA has chosen to spend a large

portion of these remaining funds on professional relations. These service priorities were determined in an attempt to mediate effects on the costs and the delivery of health care to beneficiaries.

Y-5.

Mr. Young: Mr. Secretary, has the Health Care Financing Administration prepared a plan to answer this potential backlog of unanswered inquiries and unresolved disputes?

Secretary Sullivan: Yes. As a result of funding limitations Contractor responses to beneficiary and provider inquiries will be severely limited. Contractors will increasingly use audio-response units (ARUs) to respond to beneficiary and provider inquiries. HCFA estimates that Contractors will receive 30.4 million inquiries in FY 1992, but will respond to only 8.6 million of them unless they are able to increase usage of ARUs and to identify other innovative approaches. HCFA's intent is to provide an adequate level of telephone service for beneficiary and provider inquiries.

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HEALTH CARE FINANCING ADMINISTRATION

ABORTIONSPart I - Background

HHS's Appropriations Acts have contained restrictions on the Department's funding of abortions since the Appropriations Act for FY 1977. HHS was enjoined by a Federal District Court from enforcing the FY 1977 restrictions until August 4, 1977. Consequently, the Department provided funding for all abortions which were covered under a State's plan that were performed through that date. The appropriations restrictions, commonly known as the Hyde Amendment restrictions, have governed HHS's funding of all abortions performed after August 4, 1977, except for those abortions performed during the period February 19 through September 19, 1980. Federal funding was available for all medically necessary abortions performed during that period under the criteria set forth by the District Court for the Eastern District of New York in Harris v. McRae, 448 U.S. 297 (1980).

The following excerpts from instructions issued by HHS set forth the rules under which the Department has funded abortions performed after August 4, 1977, with its appropriations for FY 1977 through FY 1980.

1. For abortions performed after August 4, 1977, and for which funds appropriated by the appropriations act for FY 1977 or the continuing resolutions which appropriated funds through December 1, 1977, are used to pay the claim:

". . . where the attending physician, based on his or her professional judgment, has certified in writing that the abortion is necessary because the life of the mother would be endangered if the fetus were carried to term."
2. For abortions performed after August 4, 1977, and prior to February 14, 1978, and for which funds appropriated by P.L. 95-205 (appropriations act for FY 1978) or P.L. 95-480 (appropriations act for FY 1979) are used to pay the claim:
 - (a) where the attending physician, based on his or her professional judgment, has certified in writing that the abortion is necessary because the life of the mother would be endangered if the fetus were carried to term;

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- (b) where two physicians, based on their professional judgment, have certified in writing that severe and long lasting physical health damage to the mother would result if the pregnancy were carried to term; or
- (c) for the victims of rape or incest, when such rape or incest has been reported promptly to a law enforcement agency or public health service.

The Department will accept any reasonable interpretation of those provisions for abortions covered under paragraph 2.

3. For abortions performed on or after February 14, 1978, and prior to August 21, 1978, and for which funds appropriated by P.L. 95-205 or P.L. 95-480 are used to pay the claim:

- (a) where a physician has found, and so certified in writing to the State agency, that on the basis of his or her professional judgment, the life of the mother would be endangered if the fetus were carried to term;
- (b) where two physicians have found, and both certified in writing to the State agency, that on the basis of their professional judgment, severe and long lasting physical health damage to the mother would result if the pregnancy were carried to term; or
- (c) for the victims of rape or incest, if the State agency has received signed documentation from a law enforcement agency or public health service stating that:
 - (i) the person upon whom the medical procedure was performed was reported, within sixty (60) days of the incident, to have been the victim of an incident of rape or incest; and
 - (ii) the report included the name, address, and signature of the person who reported the rape or incest.

4. For abortions performed on or after August 21, 1978, and for which funds appropriated by P.L. 95-205 or P.L. 95-408 are used to pay the claim:
- (a) where a physician has found, and certified in writing to the State agency, that on the basis of his or her professional judgment, the life of the mother would be endangered if the fetus were carried to term. The certification must contain the name and address of the patient;
 - (b) where two physicians have found, and certified in writing to the State agency, that on the basis of their professional judgment, severe and long-lasting physical health damage to the mother would result if the pregnancy were carried to term. The certification must contain the name and address of the patient. At least one of the two physicians must also certify that he or she is not an "interested physician." An "interested physician" is one:
 - (i) whose income is directly or indirectly affected by the fee paid for the performance of the abortion; or
 - (ii) who is the spouse of, or another relative who lives with, a physician whose income is directly or indirectly affected by the fee paid for the performance of the abortion; or
 - (c) for the victims of rape or incest, if the State agency has received signed documentation from a law enforcement agency or public health service stating:
 - (i) that the person upon whom the medical procedure was performed was reported to have been the victim of an incident of rape or incest;
 - (ii) the date of the incident;
 - (iii) the date of the report, which must be within sixty (60) days of the incident;
 - (iv) the name and address of the victim and the name and address of the person making the report (if different from the victim); and
 - (v) that the report included the signature of the individual who reported the incident.

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The continuing resolutions which made funds available for FY 1980, P.L. 96-86 signed October 12, 1979, and P.L. 96-123 signed November 20, 1979, removed the exception which allowed payment for abortions in those instances where severe and long lasting physical health damage to the mother would result if the pregnancy were carried to term when so determined by two physicians. Thus, Federal funding for abortions was prohibited except: (1) where the life of the mother would be endangered if the fetus were carried to term, and (2) for such medical procedures necessary for victims of rape or incest, when such rape or incest has been reported promptly to a law enforcement agency or public health service. Regulations implementing P.L. 96-86 were published at 42 CFR, part 441, on October 26, 1979. These regulations also applied to expenditures for abortions under P.L. 96-123 because the provision in that act governing abortions was similar to the one contained in P.L. 96-86.

On January 15, 1980, the District Court for the Eastern District of New York declared the Hyde Amendment unconstitutional insofar as it precluded payments for medically necessary abortions. That decision became effective on February 19, 1980, when the Supreme Court refused to extend a stay of the district court order. Federal funding then became available for all medically necessary abortions performed on or after February 19. The Supreme Court decision of June 30, 1980, reversed the district court's decision on the constitutionality of the Hyde Amendment. The petition for rehearing filed by the plaintiffs in the McRae case delayed the effective date of the Supreme Court's decision, leaving the district court order on payments for abortions in effect. The Supreme Court denied the appellee's petition for a rehearing in the McRae case on September 17, 1980, and the district court's order was vacated on September 19, 1980. Therefore, the availability of Federal funding for abortions performed after September 19, 1980, was subject to the FY 1980 Hyde Amendment restrictions; i.e., Federal funds under Medicaid were available only for abortions performed in life endangering circumstances and abortions performed in instances of promptly reported rape or incest.

On October 1, 1980, the President signed a joint resolution making continuing appropriations available for FY 1981 through December 15, 1980, or until the enactment of a subsequent appropriation. This resolution contained language which changed the conditions under which Federal funding was available for abortions under Medicaid. During FY 1980, Federal funds were available for abortions necessary for the victims of rape or incest when the rape or incest was reported to a law enforcement agency or public health service within 60 days.

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Under the FY 1981 resolution, Federal funds were available for abortions necessary for the victims of rape when the rape had been reported within 72 hours to a law enforcement agency or public health service. Federal funds were also available for abortions necessary for the victims of incest. There was no longer a reporting requirement for victims of incest. In cases of incest, Federal funding was available when the State agency had received a physician's written statement that the physician had been informed that the patient was a victim of incest. As in FY 1980, Federal funds continued to be available for abortions where the life of the woman would be endangered if the fetus were carried to term.

On June 5, 1981, the President signed the Supplemental Appropriations and Rescission Act of 1981. Under this act, Federal Financial Participation (FFP) is no longer available for abortion claims paid after June 5, 1981, for victims of rape or incest. Federal funds continue to be available for abortions where the life of the mother would be endangered if the fetus were carried to term.

Subsequent congressional measures have continued to make Federal funds available for abortions where the life of the woman would be endangered if the fetus were carried to term. See P.L. Nos. 97-51, 97-92, 97-276, 97-377, 98-107, 98-139, 98-619, 99-107, 99-154, 99-434, 99-464, 99-465, 99-491, 99-500, 99-591, 100-202, 100-436, 101-166 and 101-517.

Part II - Data on Medicaid Financed Abortions

Following the implementation, on February 14, 1978, of regulations which resulted from the Hyde Amendment, a specific reporting procedure was developed for reporting information on Medicaid financed abortions. Data are reported quarterly by the States on the numbers of abortions and the allowable abortion-related expenditures. Data on the number of reported abortions for FYs 1978 - 90 are given in table 1 while expenditure amounts are given in table 2.

Since February 14, 1978, 60,121 Medicaid financed abortions have been reported by 47 jurisdictions through September 30, 1990. Total Medicaid expenditures, including Federal and State shares, for abortions have been \$16,834,828 during the period February 14, 1978 through September 30, 1990. Eight jurisdictions (American Samoa, Arizona, Hawaii, Michigan, New York, the Northern Mariana Islands, Puerto Rico, and the Virgin Islands) have not claimed Federal funds for abortions. California has submitted claims for FFP for abortions but has subsequently withdrawn these claims.

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Of the 56 jurisdictions which reported for the period October 1, 1989 through September 30, 1990 (FY 1990), 17 jurisdictions claimed FFP under the Medicaid program for 69 abortions at a cost of \$95,167, including both Federal and State shares. By comparison, 13 jurisdictions claimed FFP under the Medicaid program in FY 1989 for 67 abortions at a cost of \$90,606, including both Federal and State shares. All abortion claims are subject to review by regional office staff. All claims found not to meet the applicable Federal criteria for FFP will be either withdrawn by the State or disallowed by HCFA.

The Health Care Financing Administration has not collected information on the number of abortions provided to Medicaid recipients where the State did not claim FFP, or on the number of federally financed Medicaid abortions prior to the implementation of the regulations on the Federal financing of abortions on February 14, 1978.

The abortion data in the attached tables reflect the most current information available as of November 21, 1990. Because States submit revised abortion claim data, the data contained in this report may differ with information contained in reports previously issued.

01/07/91

TABLE 1
TOTAL NUMBER OF REPORTED MEDICAID ABORTIONS BY STATE AND FEDERAL FISCAL YEAR
FEBRUARY 14, 1978 - SEPTEMBER 30, 1990 1/

	TOTAL	FY 78 2/	FY 79	FY 80	FY 81	FY 82	FY 83	FY 84	FY 85	FY 86	FY 87	FY 88	FY 89
TOTAL	60,121	1,335	3,675	33,625	17,495	783	856	893	865	232	91	135	67
ALABAMA	599	16	53	203	226	15	20	17	10	12	7	18	2
ALASKA	94	94	0	0	0	0	0	0	0	0	0	0	0
AMERICAN SAMOA 3/	0	0	0	0	0	0	0	0	0	0	0	0	0
ARIZONA 4/	0	0	0	0	0	0	0	0	0	0	0	0	0
ARKANSAS	325	9	6	204	72	10	6	9	5	3	1	0	0
CALIFORNIA	0	0	0	0	0	0	0	0	0	0	0	0	0
COLORADO	2,136	121	217	816	516	178	148	66	74	0	0	0	0
CONNECTICUT	1,394	77	223	693	336	21	8	18	9	7	2	0	0
DELAWARE	328	0	1	276	29	1	3	2	6	6	2	2	0
DISTRICT OF COLUMBIA	2,759	0	0	2,417	342	0	0	0	0	0	0	0	0
FLORIDA	1,315	12	6	735	484	35	13	3	8	13	6	0	0
GEORGIA	860	9	8	771	17	26	5	3	0	7	6	6	2
GUAM	5	0	1	4	0	0	0	0	0	0	0	0	0
HAWAII	0	0	0	0	0	0	0	0	0	0	0	0	0
IDaho	99	15	7	37	16	3	2	3	6	1	2	7	0
ILLINOIS	3,217	205	138	2,143	665	19	20	5	8	2	2	5	5
INDIANA	541	4	0	512	13	2	1	7	1	1	0	0	0
IOWA	336	0	13	136	129	11	10	1	8	6	5	9	8
KANSAS	436	0	20	378	20	3	3	1	0	1	2	5	3
KENTUCKY	28	0	6	4	7	0	0	0	0	0	4	6	1
LOUISIANA	268	0	0	113	155	0	0	0	0	0	0	0	0
MAINE	272	2	6	126	105	6	3	0	7	5	5	5	2
MARYLAND	4,260	90	168	3,035	958	9	0	0	0	0	0	0	0
MASSACHUSETTS	8,800	0	1,137	4,527	3,129	7	0	0	0	0	0	0	0
MICHIGAN	0	0	0	0	0	0	0	0	0	0	0	0	0
MINNESOTA	1,593	0	0	949	604	13	2	2	4	3	3	9	4
MISSISSIPPI	13	12	1	0	0	0	0	0	0	0	0	0	0
MISSOURI	49	0	48	0	1	0	0	0	0	0	0	0	0
MONTANA	21	0	0	0	3	0	0	2	2	13	1	0	0
NEBRASKA	114	0	1	18	81	5	4	2	1	2	0	0	0
NEVADA	122	0	2	95	22	1	1	0	1	0	0	0	0
NEW HAMPSHIRE	84	1	5	51	27	0	0	0	0	0	0	0	0
NEW JERSEY	4,269	56	94	2,426	1,685	8	0	0	0	0	0	0	0
NEW MEXICO	232	2	6	143	79	2	0	0	0	0	0	0	0
NEW YORK	0	0	0	0	0	0	0	0	0	0	0	0	0
NORTH CAROLINA	1,438	9	8	934	395	17	11	22	11	12	5	4	10
NORTH DAKOTA	6	1	0	1	0	1	3	0	0	0	0	0	0
N. MARIANA 5/	0	0	0	0	0	0	0	0	0	0	0	0	0
OHIO	9,396	410	1,003	3,065	2,741	273	509	665	650	8	12	41	19
OKLAHOMA	356	19	182	77	76	1	1	0	0	0	0	0	0
OREGON	1,341	9	77	675	534	9	19	12	6	0	0	0	0
PENNSYLVANIA	9,481	95	134	5,651	3,347	52	31	26	37	108	0	0	0
PUERTO RICO	0	0	0	0	0	0	0	0	0	0	0	0	0
RHODE ISLAND	5	1	2	0	2	0	0	0	0	0	0	0	0
SOUTH CAROLINA	511	19	12	352	51	23	13	7	4	6	8	8	8
SOUTH DAKOTA	1	1	0	0	0	0	0	0	0	0	0	0	0
TENNESSEE	388	19	2	256	84	0	1	3	0	6	10	5	2
TEXAS	73	12	7	45	9	0	0	0	0	0	0	0	0
UTAH	280	2	1	184	60	16	11	6	0	0	0	0	0
VERMONT	194	3	13	89	81	2	0	2	0	2	2	0	0
VIRGIN ISLANDS	0	0	0	0	0	0	0	0	0	0	0	0	0
VIRGINIA	124	5	23	48	13	5	3	5	5	6	6	5	0

01/07/91

TABLE 1
TOTAL NUMBER OF REPORTED MEDICAID ABORTIONS BY STATE AND FEDERAL FISCAL YEAR
FEBRUARY 14, 1978 - SEPTEMBER 30, 1990 1/

	TOTAL	FY 78 2/	FY 79	FY 80	FY 81	FY 82	FY 83	FY 84	FY 85	FY 86	FY 87	FY 88	FY 89
WASHINGTON	350	0	43	33	274	0	0	0	0	0	0	0	0
WEST VIRGINIA	3	3	0	0	0	0	0	0	0	0	0	0	0
WISCONSIN	1,534	1	1	1,402	107	9	5	4	2	2	0	0	1
WYOMING	2	1	0	1	0	0	0	0	0	0	0	0	0

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- 5/ NO MEDICAID PROGRAM IN EFFECT UNTIL FY 1979.

01/07/91

TABLE I
TOTAL NUMBER OF REPORTED MEDICAID ABORTIONS BY STATE AND FEDERAL FISCAL YEAR
FEBRUARY 14, 1978 - SEPTEMBER 30, 1990 1/

	FY 90
TOTAL	69
ALABAMA	5
ALASKA	0
AMERICAN SAMOA 3/	0
ARIZONA 4/	0
ARKANSAS	0
CALIFORNIA	0
COLORADO	4
CONNECTICUT	0
DELAWARE	2
DISTRICT OF COLUMBIA	0
FLORIDA	0
GEORGIA	0
GUAM	0
HAWAII	0
IDaho	2
ILLINOIS	5
INDIANA	1
IOWA	1
KANSAS	3
KENTUCKY	5
LOUISIANA	0
MAINE	3
MARYLAND	0
MASSACHUSETTS	0
MICHIGAN	0
MINNESOTA	9
MISSISSIPPI	0
MISSOURI	0
MONTANA	1
NEBRASKA	0
NEVADA	0
NEW HAMPSHIRE	0
NEW JERSEY	0
NEW MEXICO	0
NEW YORK	0
NORTH CAROLINA	4
NORTH DAKOTA	0
N. MARIANA 5/	0
OHIO	0
OKLAHOMA	2
OREGON	0
PENNSYLVANIA	0
PUERTO RICO	0
RHODE ISLAND	0
SOUTH CAROLINA	10
SOUTH DAKOTA	0
TENNESSEE	7
TEXAS	5
UTAH	0
VERMONT	0
VIRGIN ISLANDS	0
VIRGINIA	0

01/07/91

TABLE 1
TOTAL NUMBER OF REPORTED MEDICAID ABORTIONS BY STATE AND FEDERAL FISCAL YEAR
FEBRUARY 14, 1978 - SEPTEMBER 30, 1990 1/

	FY 90
WASHINGTON	0
WEST VIRGINIA	0
WISCONSIN	0
WYOMING	0

- 1/ DATA FOR THIS REPORT ARE TAKEN FROM THE 64.9 FORMS SUBMITTED BY THE MEDICAID JURISDICTIONS AS PART OF THEIR QUARTERLY STATEMENT OF EXPENDITURES. THIS REPORT REFLECTS THE MOST CURRENT INFORMATION AVAILABLE AS OF NOVEMBER 21, 1990. BECAUSE THE STATES SUBMIT REVISED ABORTION CLAIM DATA, THE DATA CONTAINED IN THIS REPORT MAY DIFFER WITH INFORMATION CONTAINED IN REPORTS PREVIOUSLY ISSUED.
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- 4/ NO MEDICAID PROGRAM IN EFFECT UNTIL FY 1983.
- 5/ NO MEDICAID PROGRAM IN EFFECT UNTIL FY 1979.

01/02/91

TABLE 2
TOTAL REPORTED EXPENDITURES FOR MEDICAID ABORTIONS BY STATE AND FEDERAL FISCAL YEAR
FEBRUARY 14, 1978 - SEPTEMBER 30, 1990 1/

	TOTAL	FY 78 2/	FY 79	FY 80	FY 81	FY 82	FY 83	FY 84	FY 85	FY 86
TOTAL	\$16,834,828	\$502,546	\$1,130,955	\$6,983,816	\$4,362,651	\$447,066	\$723,719	\$767,908	\$1,252,482	\$139,066
ALABAMA	148,503	4,334	11,703	45,720	48,496	4,367	8,849	5,856	1,982	2,542
ALASKA	36,331	36,331	0	0	0	0	0	0	0	0
AMERICAN SAMOA 3/	0	0	0	0	0	0	0	0	0	0
ARIZONA 4/	0	0	0	0	0	0	0	0	0	0
ARKANSAS	90,931	1,726	6,975	40,475	21,057	4,032	5,986	6,270	897	3,344
CALIFORNIA	0	0	0	0	0	0	0	0	0	0
COLORADO	496,239	19,916	39,210	166,068	106,953	41,394	76,292	27,505	18,901	0
CONNECTICUT	521,720	35,621	79,394	255,233	110,376	11,364	9,996	9,357	4,875	4,916
DELAWARE	120,120	0	617	92,912	15,767	275	1,665	2,771	2,283	2,674
DISTRICT OF COLUMBIA	371,040	0	0	336,576	34,464	0	0	0	0	0
FLORIDA	329,746	4,819	683	157,047	91,667	20,053	13,862	2,114	12,268	8,515
GEORGIA	304,964	1,687	3,327	183,283	76,402	10,427	376	659	0	4,878
GUAM	749	0	329	420	0	0	0	0	0	0
HAWAII	0	0	0	0	0	0	0	0	0	0
IDaho	28,965	2,712	1,487	8,823	2,670	866	283	792	6,695	481
ILLINOIS	529,663	66,433	28,152	319,985	98,528	8,616	3,988	729	897	336
INDIANA	132,371	2,854	0	115,518	2,470	872	150	10,077	150	280
IOWA	123,836	0	4,501	42,639	32,058	3,964	4,285	4,071	2,137	1,235
KANSAS	145,800	0	7,615	106,118	18,828	2,131	5,650	281	0	912
KENTUCKY	30,563	0	5,217	729	3,479	0	0	0	0	0
LOUISIANA	48,900	0	0	20,672	28,228	0	0	0	0	0
MAINE	108,670	1,329	1,611	45,053	35,763	1,862	5,135	0	9,141	2,582
MARYLAND	1,084,522	20,888	69,469	773,134	209,364	11,667	0	0	0	0
MASSACHUSETTS	1,117,351	0	83,049	557,590	475,911	801	0	0	0	0
MICHIGAN	0	0	0	0	0	0	0	0	0	0
MINNESOTA	293,253	0	0	142,771	142,665	2,289	108	433	1,921	393
MISSISSIPPI	780	720	60	0	0	0	0	0	0	0
MISSOURI	3,217	0	2,908	0	309	0	0	0	0	0
MONTANA	5,713	0	0	0	794	0	0	496	1,567	2,638
NEBRASKA	27,749	0	480	4,381	19,235	1,748	1,087	419	154	245
NEVADA	29,204	0	1,289	21,263	5,719	164	442	0	327	0
NEW HAMPSHIRE	12,319	100	867	7,196	4,156	0	0	0	0	0
NEW JERSEY	884,071	12,214	44,851	494,536	329,265	3,205	0	0	0	0
NEW MEXICO	43,360	386	1,195	24,378	16,808	593	0	0	0	0
NEW YORK	0	0	0	0	0	0	0	0	0	0
NORTH CAROLINA	465,748	4,676	5,489	214,195	117,549	10,842	10,370	30,313	29,865	13,242
NORTH DAKOTA	1,087	192	0	213	0	170	512	0	0	0
N. MARIANA 5/	0	0	0	0	0	0	0	0	0	0
OHIO	5,674,958	230,871	537,155	980,276	1,156,189	243,554	543,758	633,628	1,126,046	20,712
OKLAHOMA	171,623	6,964	101,461	24,538	36,223	1,218	1,219	0	0	0
OREGON	157,373	1,192	7,708	89,627	52,952	1,324	2,197	1,528	845	0
PENNSYLVANIA	2,371,222	25,366	52,750	1,242,337	911,901	33,568	9,120	18,794	20,410	56,976
PUERTO RICO	0	0	0	0	0	0	0	0	0	0
RHODE ISLAND	5,097	594	2,326	0	2,177	0	0	0	0	0
SOUTH CAROLINA	160,392	4,978	3,972	81,467	17,923	13,976	8,450	5,313	4,660	4,613
SOUTH DAKOTA	202	202	0	0	0	0	0	0	0	0
TENNESSEE	98,007	3,575	981	36,907	12,347	0	117	810	0	3,580
TEXAS	24,037	6,876	2,192	11,170	3,799	0	0	0	0	0
UTAH	55,358	520	200	34,615	11,717	3,063	3,832	1,411	0	0
VIRGINIA	48,104	1,385	6,045	18,661	15,980	161	0	500	0	2,880
VIRGIN ISLANDS	0	0	0	0	0	0	0	0	0	0
VIRGINIA	56,933	1,134	7,236	16,742	4,166	5,975	4,489	2,229	6,151	760

01/02/91

TABLE 2
TOTAL REPORTED EXPENDITURES FOR MEDICAID ABORTIONS BY STATE AND FEDERAL FISCAL YEAR
FEBRUARY 14, 1978 - SEPTEMBER 30, 1990 1/

	TOTAL	FY 78 2/	FY 79	FY 80	FY 81	FY 82	FY 83	FY 84	FY 85	FY 86
WASHINGTON	66,091	0	6,870	2,645	56,576	0	0	0	0	0
WEST VIRGINIA	868	868	0	0	0	0	0	0	0	0
WISCONSIN	310,173	883	1,581	266,365	31,720	2,525	1,501	1,552	310	332
WYOMING	1,738	200	0	1,538	0	0	0	0	0	0

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4/ NO MEDICAID PROGRAM IN EFFECT UNTIL FY 1983.

5/ NO MEDICAID PROGRAM IN EFFECT UNTIL FY 1979.

01/02/91

TABLE 2
TOTAL REPORTED EXPENDITURES FOR MEDICAID ABORTIONS BY STATE AND FEDERAL FISCAL YEAR
FEBRUARY 14, 1978 - SEPTEMBER 30, 1990 1/

	FY 87	FY 88	FY 89	FY 90
TOTAL	\$127,539	\$211,307	\$90,606	\$95,167
ALABAMA	1,952	11,936	766	15,915
ALASKA	0	0	0	0
AMERICAN SAMOA 3/	0	0	0	0
ARIZONA 4/	0	0	0	0
ARKANSAS	169	0	0	0
CALIFORNIA	0	0	0	0
COLORADO	0	0	0	745
CONNECTICUT	588	0	0	0
DELAWARE	512	644	0	17,558
DISTRICT OF COLUMBIA	0	0	0	0
FLORIDA	18,718	0	0	0
GEORGIA	2,144	12,511	9,270	0
GUAM	0	0	0	0
HAWAII	0	0	0	0
IDAHO	502	3,654	0	352
ILLINOIS	252	865	882	871
INDIANA	0	0	0	347
IOWA	13,779	6,427	8,740	2,434
KANSAS	470	2,766	1,029	1,207
KENTUCKY	6,547	14,497	184	11,389
LOUISIANA	0	0	0	0
MAINE	2,517	2,743	934	838
MARYLAND	0	0	0	0
MASSACHUSETTS	0	0	0	0
MICHIGAN	0	0	0	0
MINNESOTA	561	1,063	1,049	3,085
MISSISSIPPI	0	0	0	0
MISSOURI	0	0	0	0
MONTANA	218	0	0	876
NEBRASKA	0	0	0	0
NEVADA	0	0	0	0
NEW HAMPSHIRE	0	0	0	0
NEW JERSEY	0	0	0	0
NEW MEXICO	0	0	0	0
NEW YORK	0	0	0	0
NORTH CAROLINA	12,588	4,730	11,889	16,769
NORTH DAKOTA	0	0	0	0
N. MARIANA 5/	0	0	0	0
OHIO	34,355	130,616	37,798	0
OKLAHOMA	0	0	0	450
OREGON	0	0	0	0
PENNSYLVANIA	0	0	0	0
PUERTO RICO	0	0	0	0
RHODE ISLAND	0	0	0	0
SOUTH CAROLINA	3,259	3,825	7,956	14,865
SOUTH DAKOTA	0	0	0	0
TENNESSEE	22,226	10,759	6,705	3,803
TEXAS	0	0	0	3,663
UTAH	0	0	0	0
VERMONT	2,492	0	0	0
VIRGIN ISLANDS	0	0	0	0
VIRGINIA	3,690	4,361	0	0

01/02/91

TABLE 2
TOTAL REPORTED EXPENDITURES FOR MEDICAID ABORTIONS BY STATE AND FEDERAL FISCAL YEAR
FEBRUARY 14, 1978 - SEPTEMBER 30, 1990 1/

	FY 87	FY 88	FY 89	FY 90
WASHINGTON	0	0	0	0
WEST VIRGINIA	0	0	0	0
WISCONSIN	0	0	3,404	0
WYOMING	0	0	0	0

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Department of Health and Human Services

Report on Activities in Aging

**A Report to the
House Committee on Appropriations**

January 1991

DEPARTMENT OF HEALTH AND HUMAN SERVICES
ACTIVITIES SERVING OLDER AMERICANS
DURING 1990

In response to the many social, health, economic, and other needs of the Nation's elderly, a wide range of programs serving this age group were administered during FY 1990 by various agencies throughout the Department of Health and Human Services (DHHS). This report begins with a tabular summary of actual and expected annual expenditures for HHS activities on behalf of older Americans by each DHHS agency performing them. Narrative descriptions of those activities, as listed below, follow:

- I. Office of the Secretary
 - A. Federal Council on Aging
 - B. Administration on Aging
- II. Public Health Service
 - A. Agency for Health Care Policy and Research
 - B. Health Resources and Services Administration
 - C. Alcohol, Drug Abuse, and Mental Health Administration
 - D. National Institute of Health
- III. Health Care Financing Administration
- IV. Social Security Administration

Office of the Secretary



Federal Council On The Aging

330 Independence Avenue, S.W., Room 4280, Washington, D.C. 20201 (202) 619-2451

FACT SHEET

Members as of

June Allyson
Los Angeles, CA

Ingrid Azvedo
Chairman
Elk Grove, CA

Oscar P. Bobbitt
Austin, TX

Virgil S. Boucher
Peoria, IL

Robert L. Goldman
Oklahoma City, OK

Tessa Macaulay
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Josephine K. Oblinger
Williamsville, IL

Kathleen L. Osborne
La Jolla, CA

Raymond Raschko
Spokane, WA

Patricia A. Riley
Brunswick, ME

Gloria Sherwood
Los Angeles, CA

Norman E. Wymbs
Boca Raton, FL

E. Don Yoak
Spencer, WV

Virginia Zachert
Augusta, GA

The Federal Council on the Aging (FCoA) was created in 1973 and is authorized under the Older Americans Act (OAA), as amended. The Council is composed of 15 members selected by the President and the Congress. The 1987 reauthorization of the OAA requires that the President, Senate and House each appoint one-third of the members of the Federal Council on the Aging. Council members, who are appointed serve three-year terms, or continue to serve until they are reappointed or a successor is appointed. Members represent a broad cross-section of rural and urban older Americans, national organizations with an interest in aging, business, labor, and the general public. At least nine of the members must themselves be older individuals.

The President selects the Chairman of the Council from among the appointed members. The Council meets, at the call of the Chairman, at least quarterly.

Functions of the Council include:

- o Continually reviewing and evaluating Federal policies, programs and activities, affecting the aging, which are conducted or supported by Federal departments and agencies for the purpose of appraising their value and their impact on the lives of older Americans;
- o Serving as spokesperson on behalf of all older Americans by making recommendations to the President, the Secretary of Health and Human Services, the Commissioner on Aging, and the Congress about Federal policies regarding the aging and federally conducted or assisted programs and other activities relating to or affecting them;
- o Informing the public about the problems and needs of the aging by collecting and disseminating information, conducting or commissioning studies and publishing their results, and by issuing reports; and
- o Providing public forums for discussing and publicizing the problems and needs of the aging and obtaining information relating to those needs by holding public hearings and by conducting or sponsoring conferences, workshops, and other such meetings.
- o Preparing and providing for the President an Annual Report on the Council's activities and recommendations for the ensuing year.

Revised 12/90

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Funds for Programs on Aging
(in thousands of dollars)

	1988 Actual	1989 <u>3/</u> Actual	1990 Actual	1991 Appropriation	1992 Revised Estimate
I. Office of the Secretary (Older Americans Act)					
A. Title II, Federal Council on Aging	\$191	\$188	\$185	\$181	\$181
B. Administration on Aging Title III-B, Supportive Services	\$269,029	\$276,194	\$272,961	\$290,818	\$290,818
Ombudsman Services <u>1/</u>	<u>1/</u>	(\$988)	(\$973)	\$2,440	\$2,440
Title III, Part C-1, Congregate Nutrition	\$344,664	\$356,668	\$351,925	\$361,083	\$361,083
Title III, Part C-2, Home-delivered Meals	\$75,635	\$78,546	\$78,981	\$87,831	\$87,831
Title III, Part D, Sec. 303, In-Home Services to Frail Elderly	\$4,787	\$4,834	\$5,756	\$6,831	\$6,831
Title III, Part G, Elder Abuse Prevention	<u>2/</u>	<u>2/</u>	<u>2/</u>	\$2,927	\$2,927
Title IV, Training, Re- search and Discretionary Projects and Programs	\$23,935	\$22,253	\$25,332	\$25,941	\$25,941
Title VI, Part A, Grants to Native Americans and Alaskan Natives	\$7,181	\$9,345	\$11,107	\$13,134	\$13,134
Part B, Native Hawaiians <u>3/</u>	--	\$1,365	\$1,433	\$1,505	\$1,505
White House Conference on Aging	--	--	--	976	-0-

Footnotes . - Head Table

- 1/ Prior to FY 1991, funds for Ombudsman Services were included under Title III-B. FY 1991 is the first year that funds were appropriated separately.
- 2/ Funds for Elder Abuse Prevention were first appropriated in FY 1991.
- 3/ Titles III and IV figures reflect reprogramming of \$3,300,000 in FY 1989 to the Title VI programs. FY 1989 was the first year that the Native Hawaiian part of Title VI was funded.

SECTION I - THE ADMINISTRATION ON AGINGRole and Function of AoA

The Administration on Aging (AoA) is located in the Department of Health and Human Services (DHHS). The agency is headed by a Commissioner on Aging, who is appointed by the President with confirmation by the Senate and who reports directly to the Secretary. Joyce Berry, Ph.D., was appointed Acting Commissioner on Aging in April, 1989, following the acceptance of the previous Commissioner's resignation. She was subsequently nominated by President Bush and unanimously approved by the Senate. She was sworn in as U.S. Commissioner on Aging in March of 1990.

AoA programs are administered through a Central Office located in Washington, D.C. and ten Regional Offices. Title II of the Older Americans Act, as amended, describes the basic roles and functions of AoA. Chief among these are to serve as an effective and visible advocate for older persons (including American Indians, Alaskan Natives and Native Hawaiians) within the Department and with other agencies and organizations at the national level and to administer the programs authorized by Congress under Titles III, IV, and VI of the Act.

AoA provides policy advice to the Secretary of Health and Human Services in matters affecting older Americans and information to other Federal agencies and to Congress on the characteristics, circumstances and needs of older persons. The Agency also reviews and comments on departmental policies and regulations concerning services which affect the health and general well-being of older persons.

During FY 1990, the Administration on Aging continued its efforts to assist vulnerable older persons and their families in finding appropriate help to maintain their independence within their own communities and to delay or prevent unnecessary institutionalization. AoA believes that these efforts can best be achieved by providing State and Area Agencies on Aging with the flexibility that allows them to strengthen existing local systems to make them more visible, easily accessible, and responsive to the needs of older Americans, particularly the most vulnerable. The building and strengthening of coordinated community services systems for older persons and their families continued to be the overarching goal of efforts undertaken by AoA during

FY 1990. AoA continues to work with State and Area Agencies on Aging to develop ways in which all available resource groups (i.e., public, private and voluntary, as well as dedicated individuals) can effectively work together to create comprehensive and responsive community systems dedicated to maintaining the independence of older Americans.

Toward this end, efforts continue to focus on strengthening the roles of State and Area Agencies on Aging to help enhance, but not replace, individual self-sufficiency, family caregiving, and other traditional forms of community support. AoA recognizes that the Area Agency on Aging is the key organization that can forge the most effective and efficient linkages between existing systems of services within each community. Therefore, AoA works with State and Area Agencies on Aging to strengthen efforts that will build a system of services that provide a continuum of care for older persons, tailored to meet the needs and circumstances of individual communities.

AoA - An Effective Advocate For Older Persons

" Celebrate America's Coming of Age " was the theme for the 1990 Older American's Celebration in May and the Silver Anniversary of the Older Americans Act which was signed into law on July 14, 1965. This theme focuses on the fact that the aging of our population is changing not only the way we live and work but the types of services, products, and housing that we need. The "Aging of America" is also changing our individual and family life, our community structure, and our expectations of what our Nation's institutions should provide and how they should provide it.

It is vitally important that we, as a Nation, plan for the needs of the increasing number of persons who will be older Americans in the 21st century. We must also recognize that there is a vast reservoir of talent, knowledge, and expertise that older Americans offer our Nation, and begin to make better use of their valuable resources in new and innovative ways.

As the focal point within the Federal government for aging-related concerns, the Administration on Aging provides leadership to other Federal agencies, the national network on aging, and other public and private sector agencies, organizations and corporations relative to their efforts on behalf of older persons. Toward this end, AoA continues to develop and implement a variety of special initiatives aimed at improving the quality of life for older persons.

Goals for Fiscal Year 1991 and Beyond

In Fiscal Year 1989 the Administration on Aging (AoA) published eight goals which were the outcome of an extensive dialogue between AoA and other members of the aging community. That dialogue continued after publication of the goals and, in December, AoA convened a Future Directions Workshop, where more than 60 members of the aging community met to formulate recommendations on how AoA should proceed to set its priorities and allocate its resources in order to begin implementation of those eight published goals. The FY 1990 Discretionary Funds Announcement and the AoA 1990 Annual Work Plan reflected this continuing dialogue as well as many of the recommendations made by the participants of the Future Directions Workshop.

The eight goals provide a framework for a rich and ambitious agenda of action both for AoA and the agencies of the aging network. During FY'90, AoA took the first steps in setting in motion multi-year initiatives designed to achieve the published goals. Likewise aging network agencies initiated action directed to that same objective.

In FY 1991, AoA and the aging network will continue to build upon the groundwork provided by these goals. An action agenda will be pursued which will result in concrete achievements that benefit the lives of older persons. Consequently, AoA is reissuing the goals published last year and adopting them as the policy and program framework for AoA and the aging network during FY 1991. The goal areas are: (1) Public/Private Partnerships, (2) Older Persons as a Resource, (3) Strengthening the Family and Generational Bonding, (4) Prevention and Alternatives to Institutional Care, (5) Promotion and Enhancement of Effective Community Based Service Systems, (6) Targeting - Strategic Resource Allocation, (7) Manpower Development and (8) Preparing for the 21st Century - Challenges and Opportunities of an Aging Society. (See Appendix VI for full Statement of Goals for 1991 and beyond.)

Commissioner on Aging Forums

In FY 1990, the U.S. Commissioner conducted five field forums to obtain the views of knowledgeable individuals and organizations concerning the reauthorization of the Older Americans Act. The Commissioner received testimony from the directors and staff of State and Area Agencies on Aging, service providers, elderly consumers of services, and representatives of national, State and local organizations in the field of aging.

At the forums, participants were provided an opportunity to express their views on nutrition and supportive services, research, demonstrations and training, and Native American Programs. The forums were held in Denver, Colorado, Atlanta, Georgia, San Francisco, California, Philadelphia, Pennsylvania, and Chicago, Illinois.

Topics presented seemed to be shaped by a sense that the size and needs of the elderly population are increasing, while the buying power of the funds available has decreased. In fact, the numbers of the elderly (60+) increased during the last 10 years from 25.7 million to 31.6 million people, an increase of 23%. During those 10 years, the AoA budget increased incrementally, but the buying power of the AoA budget declined by 36%. The statements by forum participants often described strains resulting from increasing numbers of older persons in need of various community-based services.

Forum participants noted that the numbers of persons in the "old-old" (85+) category are growing much faster than the elderly population in general. The changing older population is placing increasing demands and strains on American families. Families are estimated to provide over 75% of the care provided to the elderly. Therefore, the maintenance or enhancement of family involvement in the care of older family members emerges as an increasingly important role of community service systems for the elderly.

There was substantial discussion at the forums of potential supplemental resources for Older Americans Act programs and ways in which the Act can be amended to more easily access resources. There was some discussion of private sector firms as potential purchasers of services on behalf of their employees who are caregivers and as a source of contributions to expand community services. Also, there is a widespread conviction that the National Network on Aging can increase its already impressive use of volunteers. To increase services for those most in need, there was a discussion of requiring elderly persons with the ability to pay to participate in the cost of services. There was general opposition to increasing the age of eligibility for services as a means of diminishing the scale of the service population. However, there was widespread support for other means of targeting services to these older individuals who are in greatest economic or social need, with particular attention to low-income minority older persons. One possibility that was discussed is to require that intra-State funding formulas required under the Act contain at least one factor based on the proportion of low-income minority elderly in each planning and service area.

Community Achievement Awards

For the third year, the Administration on Aging recognized communities which have made significant progress in developing exemplary systems of service for older Americans. These awards are determined through a competitive process wherein each State is invited to nominate one of its communities for an award.

The focus for the 1990 Community Achievement Award Initiative was public/private partnerships. The award winning partnerships were expected to demonstrate accomplishments in enhancing or expanding services for older persons in ways which could be replicated by other communities.

Among 29 competitive nominations, communities in 10 States were judged to have developed exemplary public/private partnerships (Alabama, California, Massachusetts, North Carolina, Oklahoma, Pennsylvania, Puerto Rico, Rhode Island, Texas, and Utah). These partnerships improved or expanded services for older persons in areas of housing, nutrition, health, intergenerational programs, outreach, transportation, day care, and recreational services. Each of these States received grants of approximately \$40,000 for the implementation of follow-up activities all designed to promote additional public/private partnerships within the State. The creativity, foresight, generosity and hard work of thousands of individuals and the commitment of business, corporations, public organizations, and civic groups made these award-winning partnerships possible.

AoA developed a brochure which describes each of the award-winning community public/private partnerships. Copies of the brochure have been sent to each State use use in the promotional activities.

Each year, the Administration on Aging honors Community Achievement Award winners in a publicized ceremony in Washington, D.C. Additionally, the initiative has generated much publicity in the award-winning communities and States. Wide media coverage has been reported. Further, Community Achievement Award honorees have been recognized through proclamations from State Governors, Members of Congress, and have received recognition at meetings and annual conferences of organizations concerned with Aging issues.

Since the Community Achievement Awards initiative was implemented in 1988, a total of 33 different communities across the nation have received awards.

The Federal Interdepartmental Task Force on Aging

At the national level, AoA's leadership role places major emphasis on developing collaborative relationships with other Federal agencies to facilitate the development of methods to achieve a coordinated response to the needs, problems, and concerns of older persons. In this regard, AoA established the Federal Interdepartmental Task Force on Aging and convened the first meeting on June 20, 1990. The primary mission of the Task Force is to identify issues for policy and program coordination and to develop collaborative interdepartmental approaches in preparation for the changing and growing elderly population. The Task Force is comprised of representatives from the Department of Education, Department of Veterans Affairs, Department of Labor, Department of Housing and Urban Development, Department of Transportation, Department of Agriculture, Social Security Administration, Health Care Financing Administration, National Institute on Aging, Family Support Administration, Health Resources and Services Administration, and the Food and Drug Administration. The Task Force established four work groups, Housing, Employment/Volunteers, Health, and In-home and Community-Based Care Services. The work groups have convened meetings to identify and select issues of major concern in the designated subject area, prioritize issues, develop action plans and report recommendations to the Task Force.

Housing

Coordination of services to those persons living in Federally assisted housing is of growing importance as residents "age in place." On August 10, AoA signed a Memorandum of Understanding (MOU) with the Farmers Home Administration (FmHA) of the Department of Agriculture. The focus of the MOU is to promote the well-being of older persons by providing a coordinated, integrated response to the housing and supportive service needs of older persons, particularly those programs serving the rural and low-income elderly. Specific activities will be developed for implementation during FY 1991.

AoA is in the final stages of negotiating with HUD for the development of an Interagency Agreement. The goal of the proposed agreement is to increase the capacity of managers of Federally-assisted housing to more effectively serve the frail elderly residents through the provision of supportive services which will enable these residents to continue to live independently.

Additionally, AoA's regional offices in Boston and Atlanta each convened a major conference with HUD and FmHA where the issues of housing for the elderly, aging in place and supportive services were addressed. All three agencies felt that these conferences were timely and successful.

Another problem which is becoming more prevalent among older persons is homelessness. AoA worked with the Interagency Council on the Homeless concerning State and local programs for elderly homeless persons. Some of the State and Area Agencies on Aging have developed special projects to reach homeless elderly persons through the provision of case management and nutrition services in the skid row areas and have worked with local and city governments to find shelter for homeless elderly persons.

The Title IV Research and Demonstration Program of AoA is one mechanism which we use to provide useful information and materials to the field. In the housing area, ten demonstration grants were awarded under priority area 5.1, "Supportive Services for the Elderly in Federally Assisted Housing." These projects will be explained further under Title IV-B Research and Demonstration Projects of the Annual Report.

Employment

During FY 1990, AoA signed a MOU with the Employment and Training Administration (ETA) to facilitate cooperation between the two agencies and to assist States and local communities in improving linkages between human service programs, and to achieve an integrated response to increasing employment and training opportunities for older persons. The MOU will develop initiatives to support the following objectives: (1) To encourage cooperation and collaboration between the service delivery systems supported by ETA and AoA in providing training, retraining, and employment services for older workers; (2) To encourage employers to hire, train, and retain older workers; (3) To reduce institutional barriers which limit opportunities for older workers to remain in or reenter the workforce; (4) To promote research, demonstration, and training activities and the dissemination of information that foster improved employment opportunities for older persons.

Representatives of ETA and AoA have met to discuss collaborative activities to support MOU. The two agencies have exchanged program information for dissemination to respective networks.

Volunteers: AoA/ACTION Collaboration

The Older Americans Act encourages collaborative efforts between the Administration on Aging and the ACTION agency in the development and expansion of volunteer opportunities for older persons through innovative program activities and initiatives. An Interagency Agreement with ACTION was signed on September 10 to sponsor a jointly funded, three-year program effort to demonstrate innovative approaches to gain private sector support to expand the number of Senior Companions providing in-home services to homebound vulnerable older persons. This expansion of the Senior Companion Program will provide new opportunities for older persons to engage in meaningful and useful volunteer activities. Eleven grants to State Agencies on Aging were funded in collaboration with appropriate Area Agencies on Aging and Senior Companion Programs. The State Agencies on Aging which received a grant designated existing Senior Companion projects as demonstration sites. ACTION also awarded a three-year contract for the conduct of a joint AoA/ACTION evaluation of the demonstrations to expand the Senior Companion Program.

Transportation

On June 11, 1990, the AoA signed a new Memorandum of Understanding with the Urban Mass Transportation Administration. The objectives of the agreement are (1) To improve the coordination of transportation services funded under the Urban Mass Transportation Act of 1964, as amended, and the Older Americans Act of 1965, as amended, which relate to older persons, including the low-income, minority, disabled, rural, and other "hard to reach" elderly; (2) To promote coordination of funding sources at the State and local levels between the network on aging and the transportation network and to encourage both networks to collaborate with agencies and community leaders in order to promote the development of responsive transportation systems; (3) To identify and explore ways to remove Federal barriers to coordination of transportation services to older persons, with particular attention to the low-income, minority, disabled, rural, and other "hard to reach" elderly; (4) To facilitate the development of information sharing activities at the national, regional, and State levels among all parties involved in elderly and handicapped transportation, particularly, information on mechanisms for utilizing the private sector; (5) To promote the development of volunteer rural transportation service systems; (6) To develop research, demonstration, training, technical assistance, and dissemination activities to promote the effective provision of transportation services for older persons. In addition, AoA and

UMTA will also explore linkages with other organizations administering programs which impact on transportation services for the elderly and ways to meet the transportation service needs of frail elderly Indians residing in non-reservation areas in order to provide access to needed nutrition and health care services.

Fire Safety

A fire in the home still remains as one of the greatest fears of an older person. During FY 1990, AoA undertook several initiatives in the area of fire safety. AoA participated in a national fire safety teleconference in April sponsored by the the Federal Emergency Management Agency (FEMA), Emergency Education Network (EENET). The program centered around the "Let's Retire Fire: A Fire Safety Program" with discussions on senior citizen fire problems, reaching and teaching older Americans, public fire education and fire safety materials. Also, discussions took place with the Consumer Product Safety Commission on the fire safety issues related to elderly nightware. As a result, a one page flyer addressing prevention tips for senior citizens has been developed. This flyer will be ready for distribution in FY 1991 along with a technical assistance package on fire safety for the Aging Network. and this technical assistance package will be ready for distribution in FY 1991.

Additionally, AoA entered into the second year of the Interagency Agreement between the Administration on Aging and the National Institute for Standards and Technology-Fire Safety in Board and Care Homes. The objective of this agreement is to assure a high level of fire safety in board and care homes and to decrease the cost of achieving such safety. Under this agreement, AoA is participating jointly with the Department of Education, ADD, HCFA, and others, in the funding of a two-year project to evaluate the fire safety evaluation system in board and care homes and to foster the use of Chapter 21 of the Life Safety Code. The objective of the project is to determine the scope of the current use and the degree to which Chapter 21 is achieving the desired goals. The project will provide information regarding whether or not the use of the Chapter 21 model requirements provides a high level of safety at reasonable cost. Currently under review within AoA is a draft report on the incidence of fire-related deaths and injuries in board and care homes.

National Survey on Recreation and the Environment

AoA has been part of a Work Group with the U.S. Department of Commerce, National Oceanic and Atmospheric Administration and the U.S. Department of Agriculture, Forest Service. The goals of the Work Group are to establish benchmark data to help policy makers and decision-makers understand recreational use of public attitudes toward our national natural resources. A portion of the survey will replicate previous National Recreation Surveys, enabling scientists to identify recreation trends over a 30 year period dating back to 1960. Currently, the National Survey on Recreation and the Environment (NSRE) is soliciting sponsors for this nationwide research effort. Administration of the questionnaires is planned for early 1992 and continue through Spring of 1993. Reporting of the results will be completed in 1994.

Developmental Disabilities

In support of the Memorandum of Understanding between the Administration on Aging (AoA) and the Administration on Developmental Disabilities (ADD), AoA and ADD cosponsored an international meeting on research and practices in the area of aging and developmental disabilities. This meeting was held in conjunction with the November 1990 Annual Meeting of the Gerontological Society of America. Other cosponsors of the meeting were the American Association of Mental Retardation, the Association for Gerontology in Higher Education and the Joseph P. Kennedy, Jr. Foundation. Objectives of the meeting were to synthesize the current practice and identify areas of inquiry and program development. Meeting participants included representatives from the United States, Canada, Europe, Australia, and Hong Kong.

Also, AoA and ADD jointly funded grants under priority areas which were included in the AoA and HDS FY 1990 Discretionary Program Announcements. Grants funded are intended to improve linkages between the aging and disabilities networks at the regional, State, and local levels, and to support training initiatives in the areas of early intervention, programs to serve older persons with developmental disabilities, and community-based programs.

Collaboration with Social Security and Health Care Financing Administrations

During FY 1990, AoA, SSA, and HCFA signed a Memorandum of Understanding (MOU) to promote enhanced collaboration of aging services. AoA, SSA, and HCFA have worked together to develop

initiatives to support the following objectives - (1) to improve coordination of services funded under the program authorities of AoA, SSA, and HCFA which relate to older persons; (2) to increase public awareness of SSA and HCFA entitlement, the nutrition and supportive services programs of AoA, and other programs which promote the well-being of older persons; (3) to increase participation in SSA and HCFA entitlement programs, nutrition and supportive services programs of AoA, and other programs which promote the well-being of older persons through special outreach efforts which focus on "hard to reach" individuals such as low-income minorities, non-English speaking and rural older persons; (4) to reduce dependency on entitlement programs by improving personal financial security and increasing employment opportunities for older persons, particularly those with disabilities; (5) to improve health care for vulnerable older people.

Several activities were undertaken during FY 1990 in support of this MOU. In the interest of improving the coordination of services for older persons, AoA and SSA jointly conducted a pilot project involving SSA Field Offices and Area Agencies on Aging. **The Older Americans Service Coordination Pilot** involved regularly stationing volunteers or paid Area Agency on Aging staff in SSA Field offices several times a week. The pilot was conducted for 90 days during the summer of 1990 in the following cities, Boston, MA, New York, NY, Philadelphia, PA, Atlanta, GA, Chicago, IL, Dallas, TX, Kansas City, MO, Denver, CO, Seattle, WA, Los Angeles, CA, Cookeville, TN, and Washington, DC.

In addition, the Commissioner on Aging, the Commissioner of Social Security, and the Administrator of the Health Care Financing Administration participated in a joint discussion via the SSA Satellite Teletraining Network. The program was seen in 29 sites throughout the country and representatives from all three networks were invited to attend. Throughout FY 1990, AoA forwarded Information Memoranda to States and Area Agencies on Aging to provide them with information concerning the Memorandum of Understanding and initiatives being conducted to support objectives.

AoA and HCFA assisted SSA in the implementation of a Representative Payee project. The project objective is to increase the number of individuals and/or organizations willing to serve as volunteer representative payees for Social Security and Supplemental Security Income beneficiaries who need assistance in managing their benefit payments. AoA, SSA, and HCFA are also involved in an information exchange to keep each agency abreast of relevant changes and developments impacting older persons.

AoA, SSA, and HCFA developed and published a pamphlet that includes information about eligibility requirements for participation in Older Americans Act, Social Security, SSI, Medicaid and Medicare programs. This pamphlet will be disseminated to agencies within networks of AoA, SSA, and HCFA.

Hospital Emergency Room - Community Aging Service System Linkages

During the Fiscal Year, work was completed by the last of six (6) demonstration projects funded by AoA in FY 1987 which developed formal linkages between hospital and aging community service agencies to facilitate the safe return home of frail elderly medically discharged from an emergency room. The projects used a variety of structural and procedural alternatives to identify, screen, and refer older emergency room patients who would otherwise be at risk in performing self-care management activities at home following emergency room discharge. To overcome the structural barriers of hospital emergency rooms - facilities designed to meet urgent medical emergencies and not the complex psycho-social and chronic physiological needs of many older persons - projects trained para-professionals and placed volunteers in emergency rooms to assist hospital social workers in interviewing older patients to determine the adequacy of self-support if discharged. A number of projects developed short-term case management and personal care services for discharged persons until they could care for themselves or other longer-term supports were arranged.

The projects successfully demonstrated that previously undiscovered frail elderly could be reached by social service agencies through formal linkages to hospital emergency rooms and that such interventions could decrease repeated or inappropriate use of emergency rooms as substitutes for the family physician. They also determined, that without additional resources to maintain these linkages, they could not be sustained. Even with additional resources, persistent problems exist in the availability and response time of in-home services to meet the immediate needs of a discharged emergency room older person. The results and lessons from these demonstrations have been disseminated through reports developed by AoA and the Long-Term Care National Resource Center at the Universities of California-Los Angeles and Southern California, and publicized in a feature article to be published in the Winter 1990-91 issue of Aging magazine.

Commissioner's Meeting on Long Term Care

In April 1990, the U.S. Commissioner on Aging convened a meeting of fifty aging network executives and others from across the country to discuss: 1) current and emerging issues facing State and Area Agencies as they work to foster community based long term care, and 2) alternative approaches to addressing these issues within existing resources.

Constance Horner, Under Secretary of the U.S. Department of Health and Human Services (HHS) and Chair of the HHS Task Force on Long-Term Care and the Uninsured, provided the keynote speech in which she recognized the aging network's contributions to serving the vulnerable elderly. The Under Secretary urged the network to continue to strengthen its efforts to meet the long-term care needs of older persons while the national debate on long term care takes place.

Four broad issues were identified by the conference planners as the central focus of the meeting: (1) Access to services; (2) Consumer decision-making and protection; (3) Managing and coordinating multiple State and local programs and funding streams; and, (4) Opportunities for public and private sector collaboration. In addition, participants were asked to identify ways that the Administration on Aging could assist the aging network improve service delivery and contribute to the national long term care policy debate.

A report of the meeting, "Advances in Long Term Care" was prepared by the Brandeis University National Long Term Care Resource Center and disseminated by AoA to the aging network. This report is intended to provide a sense of the issues and approaches discussed at the meeting as well as to stimulate new thinking about system development efforts that can be undertaken at the State and local levels.

National Health Promotion: Special Initiatives and Interagency Activities

The National Health Promotion Initiative for Older Persons is a joint activity sponsored by the Administration on Aging and the Public Health Service. This multi-year activity was officially launched in 1984 with the signing of the first of several Memoranda of Understanding between the two agencies. The Initiative is designed to improve the health status of older persons and improve the quality of life of their later years.

The Initiative has three major goals: (1) maximizing the opportunities for older persons to live independently through

improvement of their health status; (2) focusing attention on health promotion and disease prevention through improved nutrition; physical fitness; smoking cessation; mental health; dental health; adult immunization; prevention of fire and smoke related accidents and injuries; driver and pedestrian safety; depression; diabetes; and hearing impairments; and (3) curtailing health expenditures caused by preventable conditions. Some specific activities conducted during FY 1990 to attain these goals are discussed below.

Smoking Cessation

The Administration on Aging, in conjunction with the Office of Smoking and Health, the Office of Disease Prevention, and the American Association of Retired Persons, launched an initiative to encourage older persons that "It's Never Too Late to Quit Smoking." The initiative, which is a follow-up to the recommendations of the 1988 Surgeon General's Workshop on Health Promotion and Aging, and the 1990 Surgeon General's Report on Smoking and Health, includes a public education and awareness campaign on the possibilities for stopping smoking at any age and will encourage older persons and their families and caregivers to seek the necessary resources to assist them in this effort.

Year 2000 Objectives

The Administration on Aging has been involved with the preparation of the Year 2000 Health Objectives for the Nation since 1988. AoA participated in the original Task Force organized by the National Institute on Aging, which had the overall responsibility for helping to develop the Objectives for older persons. AoA also reviewed, commented and made suggestions on the various drafts of the document, which was finally prepared and issued by the Office of Disease Prevention and Health Promotion, PHS, in September 1990.

Other Health Promotion Activities

The Administration on Aging supported the development and distribution of the fifth annual Health Promotion Calendar for Older Persons. Owing to the success of the prior calendars, the 1990 calendar was a joint effort between AoA, the National Council on the Aging and a private sector sponsor for the second year in a row.

The Administration on Aging again collaborated with the National Osteoporosis Foundation to produce a poster and

materials in support of National Osteoporosis Month. This activity is designed to raise national awareness of the prevalence of this disease among older persons and the possibilities which exist for prevention through modification of lifestyles. Secretary Louis Sullivan, M.D. was the keynote speaker at the annual awards banquet given by the Foundation and Dr. Joyce Berry, U.S. Commissioner on Aging, received an award for the Agency's long-standing commitment to osteoporosis education.

Health Promotion Among Minorities

The ten projects which were awarded under the FY 1989 Historically Black Colleges and Universities Initiative (HBCU) began to develop and carry out their projects. The initiative is designed to increase the awareness and motivate older minority persons to the importance of healthy behaviors and lifestyles. Each school is developing and demonstrating strategies that will ultimately promote better self-care habits among Black elderly. These strategies range from using a mobile van for health screening, health education and health counseling in rural areas; developing church-based health promotion programs; to developing six (6) videotapes and instructional guides to be broadcast on public access television. The National Resource Center on Health Promotion and Aging prepared a brochure which describes each of the individual HBCU projects.

Information and Referral

In addition to its Federal level advocacy responsibilities, AoA is also charged with assisting and supporting efforts by other components of the national network on aging to serve as effective advocates at the State level and in communities across the country. Information and referral remains a key element in AoA's strategy for enhancing the network's advocacy capability and remains the cornerstone of a comprehensive service delivery system. In an effort to strengthen the capacity of the network on aging in this area, the Administration on Aging has several efforts related to Information and Referral underway. (1) the National Association of Area Agencies on Aging, under a cooperative agreement from AoA, is pilot testing an 800 toll free Information and Referral number in select geographic areas. If the demonstration proves successful, the toll free I&R number will be expanded to include other geographical areas. (2) the National Association of State Units on Aging was awarded a grant to enhance the capacity of State Aging Information and Referral systems to meet the future needs of an aging society.

(3) The Administration on Aging is working in collaboration with the General Accounting Office (GAO) to identify exemplary local I&R systems; (4) AoA also worked with the Subcommittee to the HHS Working Group on Disability to develop recommendations and proposals to improve I&R systems for persons with disabilities; (5) AoA has been in the process of updating and revising the Caregivers Guide, "Where to Turn for Help." This booklet, which continues to receive wide circulation and distribution by public and private organizations, is aimed at providing answers to some of the most frequently asked questions about finances, health, legal and community services for the elderly.

Elder Abuse Initiative and Activities

Secretary Louis Sullivan has assigned AoA and the Assistant Secretary for Planning and Evaluation (ASPE) joint responsibility for developing a DHHS Elder Abuse Strategy, with the cooperation and assistance of other appropriate units in the Department. A DHHS Elder Abuse Task Force (consisting of the top leadership of AoA, ASPE, the Health Care Financing Administration, the Public Health Service, and the Social Security Administration) will develop a detailed plan that recommends for the Secretary's consideration and decision: (1) short term activity that would be carried out within current budget constraints and program authority and; (2) longer term policy, programmatic, and research issues.

Secretary Sullivan has made clear the commitment of the Department to take concerted action against elder abuse in both institutional and residential (home) settings. The DHHS strategy now being developed will encompass efforts to: (a) promote the prevention of elder abuse whenever and wherever possible; (b) improve the reporting, investigation, and resolution of elder abuse cases through appropriate intervention services, and; (c) point toward better monitoring and follow-up of those cases to guard against reoccurrences of elder maltreatment.

Among the activities that will be considered for inclusion in the Elder Abuse Strategy are:

- o Public awareness campaigns conducted jointly at national and State levels, keynoted by a national conference.
- o Capacity-building activities to support State systems for reporting, investigation, intervention, and resolution of elder abuse cases.

- o Training programs on how to recognize, prevent, and deal with elder abuse for such care providers and service practitioners as nursing home administrators, nurses aides, physicians, social workers, and senior center staff.
- o Judicial and law enforcement supportive activities to strengthen the roles of the courts, adult protective service agencies, nursing home survey and certification agencies, law enforcement offices, and medicaid fraud and abuse units.
- o Research and demonstration projects to advance our ability to understand and deal with elder abuse, including studies of the causes of maltreatment and testing new models for identifying, preventing, and intervening against elder abuse in both domestic and institutional settings.

Low-Income Minority Elderly

According to the most current census data available, nearly one-fourth of the total number of low-income minority elderly in the United States are concentrated in the southeastern states of Georgia, Florida, North Carolina, South Carolina, and Alabama. Nation-wide, the largest numbers of low-income minority elders live in Texas, New York, Florida, California, and Georgia. The smallest populations of low-income minority older persons reside in Vermont, New Hampshire, Maine, North Dakota, and Wyoming.

The 1987 Amendments to the Older Americans Act (OAA) required State and Area Agencies to place an increased emphasis on meeting the needs of low-income minority elderly persons. In Section 306(a)(5)(A) of the OAA, Area Plans are required to:

1. Provide assurances that preference will be given to providing services to older individuals with the greatest economic or social needs, with particular attention to low-income minority individuals;
2. Provide assurances that the Area Agency will include in agreements made with service providers a requirement that the provider will: a) specify how he/she intends to satisfy the service needs of low-income minority elders in the area served by the provider, and b) attempt to provide services to low-income minorities in at least the same proportion as they bear to the population of older individuals in the service area;

3. Identify the number of low-income minority older individuals in the planning and service area; and
4. Describe the methods used to satisfy the service needs of such minority elders.

States use a wide variety of methods to satisfy the service needs of their low-income minority individuals, including training and information dissemination, in English and other languages if needed; altering intrastate funding formulas to reach more low-income minority elders; as well as forming task forces, working with national minority organizations, and increasing minority participation on advisory councils and in the provision of services.

The Administration on Aging (AoA) has a major policy goal to develop and implement new strategies to more effectively target resources and programs on the needs of the most vulnerable older persons, with special emphasis on low-income minority elderly. We are confident that all segments of the national network of services for the elderly share our conviction that substantial improvement on this mandate can and must be achieved as a priority.

During the past fiscal year, AoA has demonstrated its commitment to targeting services to low-income minority elders through the issuance of the Policy Instructions to States, encouraging their development of programs to target services to these most vulnerable older persons. Plans are underway to establish a Commissioner's Council on Minority Participation during the current fiscal year. This Council of experts from the field of aging will focus on minority participation under the Older Americans Act and will help to ensure that the best possible policies and practices are instituted on behalf of all older persons.

Hispanic Aging Initiative

The AoA Hispanic Aging Initiative is focused on collaborative efforts among Federal, State, and community agencies, national Hispanic/aging organizations, and knowledgeable and concerned individuals--efforts aimed at improving the quality of life of Hispanic elderly. The initiative's primary focus is on public information and related efforts that better inform Hispanic elderly on how to improve their health. A related objective is to better target resources to Hispanic elderly and to increase their access to services and entitlement programs. Complementary aims are to increase the number of trained Hispanics serving in aging programs and to improve our knowledge and understanding of the Hispanic aging population.

Health Promotion and Disease Prevention

Under the objective of health promotion and disease prevention, AoA has planned or underway a range of collaborative activities with the National Institute on Aging (NIA) and others to conduct workshops and public education campaigns adapted to the cultural norms of Hispanic elderly. The AoA/NIA workshops, scheduled for December 1990 and February 1991, will develop health promotion strategies and recommendations for future research on the health practices of Hispanic elderly. Initial public education campaigns are likely to focus on 1) nutrition, 2) physical fitness, and 3) smoking cessation--important health concerns in the Hispanic community.

Other health promotion activities under the AoA Hispanic Aging Initiative include project awards to the two national Hispanic aging organizations, the Asociacion Nacional Pro Personas Mayores (ANPPM) and the National Hispanic Council on Aging (NHCoA) to develop health promotion materials and program activities for Hispanic elderly. These include brochures in Spanish on smoking cessation, diet, exercise and hypertension; television spots in Spanish on smoking cessation and healthy diet; and health promotion and disease prevention projects on cardiovascular disease and stroke, diabetes, and accidental injuries.

In addition, AoA has recently funded the Aging Assist/WQED (Metro Pittsburgh Public Broadcasting) project which will develop a six part public television series on health promotion for Spanish speaking elderly and the hearing impaired elderly. This new television series builds on an earlier AoA-funded WQED production, which also had a health promotion focus, that was designed for a general, English speaking audience.

Targeting of Services to Low Income Hispanic Elderly

AoA currently is funding a number of projects to improve access to services by Hispanic elderly. In addition to their health promotion activities, both the ANPPM and the NHCoA received two year grants to educate Hispanic elderly about their entitlement benefits. The National Council of La Raza continues a project to establish a national network of Hispanic community-based groups committed to serving the elderly. Other projects focus on access to legal services, home care services and health services, and diabetic retinopathy. Model programs and other materials developed by the National Resource Center on Minority Aging Populations will be available to improve programs serving the Hispanic elderly.

Training to Improve Services to Hispanic Elderly and Better Knowledge and Understanding of the Hispanic Aging Population

Several current Title IV-A Training projects include components to improve the skills and capacity of professionals and/or paraprofessionals to serve Hispanic elderly. Both ANPPM and NHCoA are funded to place Hispanic graduates/professionals in paid, aging-related, administrative-level traineeships. The Pasadena Hospital Association and the Edward R. Roybal Center on Applied Gerontology, in conjunction with a consortium of ten (10) local home care agencies, will train Hispanic workers to deliver home care services to the elderly. In addition, the Institute for Community Research (Hartford, Connecticut) will be developing a model information and communication program aimed at improving access to services by Hispanic elderly with Alzheimer's Disease and by their family caregivers.

USA/USSR Cooperative Activity on The Elderly

With the assistance of the Administration on Aging (AoA) and other organizations in the field of aging, the Department of State developed a comprehensive program of cooperative activities between the USA and the USSR on programs and services for the elderly. This comprehensive program involves the exchange of information concerning issues related to older persons in America and the Soviet Union, including health care, housing, social services, income security, employment, and long-term care.

The collaborative activities included a visit to America by a Soviet Delegation of six persons to participate in a comprehensive program on the elderly during April and May 1990. The National Council on Aging Conference, an Administration on Aging Overview of USA System of Programs and Services for Older Americans, and site visits to State and Area Agencies on Aging, Hospitals with Geriatric Care Units, Nursing Homes, and Housing Communities for Senior Citizens in the Baltimore and Washington Metropolitan Area were included among the planned activities for the delegation.

The Administration on Aging continues to meet regularly with the State Department, Bureau of Human Rights and Humanitarian Affairs to discuss the Soviet Union requests for assistance. One of the areas of requested assistance was in the construction and renovation of homes for the elderly. The Administration on Aging as a member of the State Department's work group contributed to a technical assistance housing proposal which was presented in Russia October 1-7, 1990.

SECTION II - TITLE III SUPPORTIVE AND NUTRITION SERVICESIntroduction

The Administration on Aging (AoA) is the lead component within the Department of Health and Human Services on all issues concerning Aging. It advocates for the needs of the elderly in program planning and policy development; provides technical assistance; issues best practices guidelines; and initiates policy relative to funding the States and Territories for the provision of services to older Americans under Title III (Grants for State and Community Programs on Aging.)

Each State Agency is required to subdivide the State into Planning and Service Areas (PSAs) and to designate within each PSA an Area Agency on Aging (AAA) to be specifically responsible for carrying out the purposes of the Act within the PSA. While most States have a statewide network of Area Agencies on Aging, fourteen States/Territories have designated their entire geographic area as a single PSA with the State agency performing the Area Agency functions because of their small geographic areas or population size.

State Agencies on Aging

The Older Americans Act intends that the State Agency on Aging shall be the leader relative to all aging issues on behalf of all older persons in the State. This means that the State Agency proactively carries out a wide range of functions related to advocacy, planning, coordination, interagency linkages, information sharing, brokering, monitoring and evaluation designed to develop or enhance services for older persons throughout the State. Fifty-seven (57) States and other jurisdictions receive support under Title III of the Act. States may elect durations of two, three or four years for State and Area Plans.

The State Agencies assure that the resources made available to Area Agencies on Aging under the Older Americans Act are used to carry out the Area Agency mission of assisting older persons in leading independent, meaningful and dignified lives in their own homes and communities as long as possible.

State and Area Agencies on Aging work to facilitate the most effective use of all community resources, both public and private, to provide for appropriate services to older persons within the many communities of the Planning and Service Area. To effectively accomplish this goal, there must be a community-wide effort with all appropriate resources, programs and personnel carefully coordinated.

Area Agencies on Aging

In FY 1989, there were over 670 Area Agencies on Aging operating under Title III of the Act. As of the end of FY 1989, there were approximately 684 Planning and Service Areas, including the 15 Single Planning and Service Areas, previously mentioned, covering whole States and Territories. An Area Agency on Aging may be a public or private organization, an Indian Tribe or a sub-State regional body. Area Agencies on Aging have the major responsibility for the administration, at the sub-state level, of Title III funds for supportive and nutrition services. Area Agencies receive their funds from the State Agency on Aging and then award grants and contracts to local supportive and nutrition service providers under an approved area plan.

Area Agencies on Aging are responsible for providing technical assistance to and monitoring the effectiveness and efficiency of, their respective service providers. Through their coordination and planning activities, Area Agencies also address the concerns of older persons at the community level. Area Agencies interact with other local public and private agencies and organizations in order to coordinate their respective activities and elicit or "leverage" additional resources to be used on behalf of older persons.

Funding State and Area Agencies on Aging

State Agencies on Aging received a total of \$709.5 million of Title III funds during FY 1990. Funds under this Title of the Act are made available to the States on a formula basis upon approval of State Plans by AoA Regional Offices. States then allocate funds to Area Agencies based upon approved Area Plans to pay up to 85 percent of the costs of supportive services and senior centers, and nutrition services. In most cases, Area Agencies on Aging then arrange with both nonprofit and proprietary service providers to deliver nutrition and other services described in the Area Plan.

In general, funds provided to Area Agencies are used for the administration and provision of a wide range of supportive and nutrition services authorized under Parts B, C and D of Title III as described in the next paragraph.

Title III Services

Title III activities conducted in the States during FY 1990 were based upon State plans ranging in duration from two to four years. In FY 1990 four separate allocations under Title

III were made to States for: (a) supportive services and senior center operations; (b) congregate nutrition services; (c) home-delivered meals; and (d) in-home services for the frail elderly. The 1987 Amendments to the Older Americans Act newly established Part D to Title III for in-home services for the frail elderly. (See Appendix II for State allotments under Title III in FY 1990).

Title III-B supportive services are designed to provide assistance to all older persons, with particular attention to older persons in greatest economic or social need. Most supportive services fall in three broad categories: access services; in-home services; and other community and neighborhood services. Access services are transportation; outreach; and information and referral. Most in-home services are homemaker; personal care; chore; and/or visiting and telephone reassurance. Community and neighborhood services include legal services; residential repair; escort services; health services; physical fitness programs; pre-retirement and second career counseling; and other services.

Data on Title III services and program operations are reflected in State Program Reports which are sent to AoA Central Office each year by the State Agencies on Aging through AoA's ten Regional Offices. The Title III State Program Reports for FY 1989 were analyzed during FY 1990. The national program statistics for FY 1989 are provided in Appendix IV. These data provide a national summary of the Title III program including such information as participation levels, expenditures, and units of service by service category. This information is responsive to Sections 207 (a)(1), (a)(2) and (a)(4), as required by the 1987 Amendments to the Older Americans Act. Selected program data are presented in the following paragraphs.

The 1987 Amendments to the Older Americans Act require the Administration on Aging to report to Congress specific information regarding the programs and activities under the Act at the end of the fiscal year. The information collected by the States in FY 1990, to be reported as called for by Sections 207 (a)(1), (a)(2) and (a)(4) is currently being analyzed and will be included in the Annual Report for FY 1991.

Title III-B Supportive Services

In FY 1989, the Title III-B program reached an estimated 7.1 million older clients in need of access, in-home, and community-based services. In FY 1989, 15 percent of all participants were racial and ethnic minorities and 40 percent were low income. In the area of access services, transportation was the most frequently provided service, followed by

information and referral, then outreach. In the area of in-home services, housekeeping assistance was reported most frequently followed by reassurance to elderly persons through visiting and telephone contacts, and then chore services. In the community-based services area, recreational services were most frequently provided, followed by education and training, escort and legal services.

Title III-C, Congregate and Home Delivered Nutrition Services

Congregate and Home-Delivered Nutrition Services, authorized by Title III-C, continue to be an integral part of the systems which communities are developing to assist their older citizens in maintaining independence and remaining in their own homes as long as possible.

Congregate Nutrition Services

Over 144 million congregate meals were served to older people and their spouses during FY 1989. In addition to Title III-C funds, these meals are also supplemented and supported by United States Department of Agriculture funds; Social Services Block Grant program funds; other Federal, State/local funds; and participant contributions. Over 2.7 million elderly received meals at congregate sites.

Home-Delivered Meals

Home-delivered meals are also critical to the maintenance of independence for older persons who are unable to participate in congregate meals programs. During FY 1989, 99.6 million meals were provided to the homebound elderly from Title III-C and other funding sources. This number represents an increase over the 94.6 million home-delivered meals served in FY 1988. A total of 775,159 older persons received home-delivered meals.

Title III-D, In-Home Services for Frail Elderly

Title III-D, In-Home Services for Frail Older Persons, was established by the 1987 Amendments to the Older Americans Act, and funds became available for the first time in FY 1988. During FY 1989, over 91,000 thousand frail older persons received in-home services under the Title III-D program.

Allotment Transfers

Under the Older Americans Act, the State Agencies on Aging have the authority to transfer limited amounts of funds among three of the Title III allotments (Parts B, C-1 and C-2) in order

to better reflect their local needs and priorities. (See Appendix III for Title III State Allotments after Transfers in FY 1990.) In FY 1990 the net transfers were as follows:

	<u>Net Transfers</u>	<u>Percent Change*</u>
Title III-B (Supportive Services)	+\$22,531,494	+8.3%
Title III-C-1 (Congregate Nutrition Services)	-\$58,466,550	-16.6%
Title III-C-2 (Home-Delivered Meals)	+\$35,935,056	+45.5%

* Transfer as percent of original allotment.

Advocacy and Partnerships

In advocating for older persons, State and Area Agencies on Aging review and comment on State and community policies, programs and issues; provide testimony at public hearings; publish reports; coordinate and provide technical assistance to other public and private agencies and organizations; and leverage resources from other Federal, State and local programs, as well as private charitable and business resources.

Non-Federal Resources and Program Income

The Title III program has evolved from a relatively simple program of community service projects for older persons into a complex and highly differentiated "national network on aging" currently consisting of 57 State Agencies and over 670 Area Agencies on Aging and more than 25,000 local nutrition and supportive service providers. These nutrition and supportive service providers are local public, private, or voluntary organizations. Not only do the State and Area Agencies on Aging use Title III monies to provide for services, they also are instrumental in leveraging other public and private monies in addressing the needs of older persons.

Title III regulations (45 C.F.R. Part 1321) require each service provider to "provide each older person [receiving services] with a full and free opportunity to contribute toward

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the cost of the service." Although AoA emphasizes through the aging network that this is not a fee and that contributions are entirely voluntary, these contributions have been steadily increasing, as follows:

FY 1981	\$ 79.0 million
FY 1982	100.8 million
FY 1983	116.7 million
FY 1984	131.7 million
FY 1985	140.1 million
FY 1986	153.9 million
FY 1987	163.6 million
FY 1988	168.1 million
FY 1989	179.0 million
FY 1990	

Ombudsman Programs

State Agencies use part of their Title III-B (Supportive Services and Senior Centers) funds and funds from other sources to establish and maintain long term care ombudsman programs at the State and sub-State levels. Through their ombudsman programs, States have addressed such issues as nursing home regulations, abuse of residents' personal funds, and restrictions on access to nursing homes. Complaint statistics and program data for the FY 1989 reporting period were analyzed during FY 1990. Some highlights of these data are as follows:

- o During FY 1989, the most recent period for which data are available, there were 1367 sub-state programs.
- o Total funding for State and local ombudsman programs in FY 1989 increased from approximately \$23.3 million in FY 1988 to about \$25.2 million. In addition to Title III-B funds, State and local governments used funds from other sources, including State, county, and local revenues, grants under Titles IV and V of the Older Americans Act, and other funding sources.

Waivers as Related to Priority Services

The Older Americans Act, as amended, requires that the Administration on Aging collect and report special information about access, in-home and legal assistance services. Section 307 (a) (22) requires that each State Agency include in its State Plan a minimum percentage of Title III-B funds which each Area Agency must expend on these services. Otherwise, the State grants a waiver to the Area Agency. Section 306 (a) (2) describes the requirements which must be met by an Area Agency when requesting a waiver from providing the required minimum amount for one or more of these priority services (access, in-home and legal assistance) and by the State Agency in granting any such waiver request.

Pursuant to Sections 207 (a) (2) and 306 (b) (2) (d) of the Act, the Administration on Aging compiled a report on waivers of priority services as required under the Act. The following provides a brief overview of the report:

The Act permits State Agencies to grant waivers to Area Agencies that have not expended the mandated minimums for priority services. The Act also requires the State Agency to follow rigorous procedures in their respective granting and review of waivers. Of the 674 Area Agencies on Aging in the country, a total of 28 waivers were granted by 8 States. All of the waivers were found to be complete. Of the 28 waivers granted by the States, one was for access, 17 were for in-home services and ten were for legal assistance.

The data suggest that there is a high level of compliance with the provisions of the Act. The States have set minimum expenditure levels for the priority services. For most Area Agencies on Aging the States report that the actual expenditure levels have been met.

It is clear that the States have taken the Congressional mandate seriously as well as the freedom to define appropriate proportion.

SECTION III - SERVICES TO OLDER NATIVE AMERICANS

TITLE VI GRANTS FOR NATIVE AMERICANS

Under Title VI of the Older Americans Act, the Administration on Aging annually awards grants to provide supportive and nutritional services for older Native Americans. When Title VI was added to the Older Americans Act in 1978, it was named "Grants to Indian Tribes." In the Older Americans Act Amendments of 1987 (P.L. 100-175, signed November 29, 1987) it was renamed "Grants for Native Americans," and a change was made to add older Native Hawaiians to the American Indians and Alaskan Natives already being served by Title VI. Title VI was divided into two parts, Part A - Indian Program, and Part B - Native Hawaiian Program. The first grant under Part B was made in Fiscal Year 1989.

In Fiscal Year 1990, under Title VI Part A, for American Indians and Alaskan Natives, there was an increase of 12 tribal organization grantees, from 181 to 193, and the funding increased from \$9,345,000 for Fiscal Year 1989 to \$11,107,961 for Fiscal Year 1990.

Under Title VI Part B, for Native Hawaiians, the funds awarded, as specified by the 1987 Amendments, increased from \$1,365,000 for Fiscal Year 1989 to \$1,433,000 for Fiscal Year 1990.

ELDERS ELIGIBLE UNDER TITLE VI

Persons eligible for services under Title VI Part A are tribal members age 60 or over living in a Tribe's Title VI service area, and members under age 60 if the Tribe has selected a younger age for "older Indian." The Older Americans Act Amendments of 1981 allowed Tribes to set a younger age for "older Indian", if considered appropriate. The 193 grantees of Title VI Part A for Fiscal Year 1990 estimated that 74,607 older Indians were eligible for services, including 59,792 age 60 or over, and 14,815 under age 60.

(See Appendix V for detailed information on grant awards by Region, including number over and under age 60 for each Tribe, and the age of "older Indian" selected.)

For services under Title VI Part B, the Native Hawaiians must be age 60 or over. Alu Like, the statewide grantee, estimated that 1,300 older Native Hawaiians were in the proposed Title VI Part B service areas on the five major islands and thus were eligible for Title VI services. The grantee estimated that there were a total of 10,876 older Native Hawaiians in the entire State of Hawaii.

SERVICES UNDER TITLE VI

The services provided by Indian Tribes under Title VI Part A were congregate and home-delivered meals, and a variety of supportive services. All grantees provided, unless other arrangements existed, the required service of information and referral. Other supportive services were provided as needed, including transportation, counseling, home assistance services, etc.

We estimate that approximately 1,700,000 meals were provided under Title VI Part A in Fiscal Year 1990, including 900,000 congregate meals, and 800,000 home-delivered meals.

Services under Title VI Part B, Native Hawaiian Program, included congregate meals, transportation, health awareness and screening, education and recreation classes, and escort services. Service centers, located on or near the Hawaiian Home Lands, were developed in Fiscal Year 1990.

CONTRIBUTION TO AoA GOALS

The Title VI program contributed to all eight of the AoA goals established for Fiscal Year 1990.

1. Public-Private Partnerships

AoA encouraged tribal organizations to seek services for older Indians from public, voluntary, and profit-making agencies, as Indians are eligible for all services available in the States, as well as the services available to them because of their status as Indians or as members of Indian Tribes.

By the end of Fiscal Year 1990, AoA had established a working relationship with the American Association of Retired Persons, a voluntary agency, on helping older Indians to obtain benefits to which they are entitled under Medicaid, Medicare, Social Security Retirement, and Supplemental Security Income.

2. Older Persons as a Resource

The Title VI Part A program regularly uses older persons, both Indian and non-Indian, as resources in the service program. Activities include assistance with meals, transportation, information and referral, chore service, etc., as well as membership on advisory committees.

3. Strengthening the Family and Generational Bonding

Title VI programs often encourage intergenerational contacts. Older Indians visit children's groups and tell stories about tribal tradition and culture.

4. Prevention and Alternatives to Institutional Care

One of the main goals of Title VI is to provide, or secure through referral, community-based services which will enable older Indians to remain in their homes. The meals and transportation services, as well as information and referral about available resources, combine to make Title VI a strong influence in the prevention of and alternatives to institutional care.

5. Promotion and Enhancement of Effective Community Based Service Systems

All the programs under Title VI provide community based services to older Indians. Title VI programs also cooperate with Title III services at some Tribes where both are available.

6. Targeting - Strategic Resource Allocation

Title VI is an example of a program which targets its resources on the needs of the most vulnerable older persons, with special emphasis on low-income minority elderly. All Title VI recipients are in a minority group, and American Indians, Alaskan Natives, and Native Hawaiians have been shown to have a high incidence of low income.

7. Manpower Development

There have been several efforts to relieve critical manpower needs in the field of aging. For two years, AoA has utilized the services of an Indian grantee to conduct leadership training sessions for new Title VI program directors. Also AoA funds an ongoing competitive contract to provide technical assistance to Title VI directors. Underlying these special efforts are the continuing technical assistance activities by AoA Regional Office staff.

Some Title VI programs also directly conduct training for persons to care for older persons, by classes in first aid, cardio-pulmonary resuscitation, nutrition and meal preparation. etc.

8. Preparing for the 21st Century - Challenges and Opportunities of an Aging Society

Tribal organizations which are recipients of Title VI have reminded the Federal Government and the public of the growing number of older Indians, and the need to begin planing for those increases now.

ADMINISTRATIVE PROCEDURES

On April 1, 1990, in an effort to reduce the paperwork burden, a change was made in the administration of grants under Title VI. Previously AoA grants had been processed by the Grants and Contracts Management Division of the Office of Human Development Services, using an annual application on Standard Form 424.

Beginning April 1, 1990, Tribes were allowed to provide a narrative plan and the applications were sent to the Regional Offices of AoA. The application period can be for two or three years, without additional application. The Regional Offices review and recommend approval of each plan for the Commissioner on Aging, who gives final approval for the entire period.

TECHNICAL ASSISTANCE

AoA awards an open and competitive technical assistance contract to aid Title VI grantees in matters of program planning and administration. The contract provides group meetings and individual on-site technical assistance. Reports from the contractor show that the grantees request technical assistance primarily on the following subjects: Title VI and Title III coordination; budget and program management; nutrition; and service development.

OFFICE FOR AMERICAN INDIAN, ALASKAN NATIVE, AND NATIVE HAWAIIAN PROGRAMS

On May 19, 1989 the Commissioner on Aging established the Office for American Indian, Alaskan Native, and Native Hawaiian Programs. This new office was charged with the responsibility to serve as the focal point within AoA for the operation and assessment of programs authorized under Title VI of the Older Americans Act (OAA) and to provide program and policy direction to the ten Regional Offices of AoA in the execution of their Title VI responsibilities. Additional functions of the Office are to serve as the effective and visible advocate on behalf of older Native Americans, to coordinate activities with other Federal departments and agencies, to administer and evaluate

grants provided under the OAA to Indian Tribes and public and nonprofit private organizations serving Native Hawaiians, and to collect and disseminate information related to the problems of older Native Americans.

INTERAGENCY TASK FORCE ON OLDER INDIANS

The 1987 Amendments in Section 134(d) directed the Commissioner on Aging to establish a permanent Interagency Task Force on Older Indians, with representatives of departments and agencies of the Federal Government with an interest in older Indians. This Task Force was established in Fiscal Year 1990. By the end of the Fiscal Year, representatives of 16 Federal departments and agencies had been appointed, and the first two meetings had been held.

The responsibility of the Task Force, as stated in the 1987 Amendments, is to report to the Commissioner at 6-month intervals on their findings and recommendations with respect to facilitating the coordination of services and the improvement of services to older Indians. The Task Force is to be chaired by the Associate Commissioner on American Indian, Alaskan Native, and Native Hawaiian Aging, who is to be appointed by the Commissioner.

SECTION IV - AOA DISCRETIONARY PROGRAMSTITLE IV-A: EDUCATION AND DEVELOPMENT PROJECTS

Sections 410 and 411 of the Older Americans Act authorize the award of grants and contracts to assist in recruiting persons, including minorities, to enter the field of aging; to train professional and paraprofessional persons employed in or preparing for employment in fields having an impact on the aging; and to provide technical assistance and other activities related training. Other sections of Title IV authorize health projects and projects in long term care.

Several of the AoA National Goals provide the organizing framework for AoA's education and development initiatives for FY 1990. These goals are:

- o Manpower Development
- o Targeting - Strategic Resource Allocation
- o Promotion and Enhancement of Community Based Service Systems
- o Prevention and Alternatives to Institutional Care
- o Public Private Partnerships
- o Strengthening the Family and Generational Bonding

Highlighted below are new and continuing education and development project activities for FY 1990 under each of these six AoA national goals:

MANPOWER DEVELOPMENT

The primary objectives of the education and training program are to improve the availability and quality of services to older persons and to help meet the critical shortages of adequately trained personnel for programs in the field of aging. Activities supported under this program are intended to encourage and develop State and community leaders dedicated to these objectives and the creation and implementation of responsive community-based systems of services for the elderly. In FY 1990, AoA's new awards focused on a cross section of target groups that will address a variety of training issues and techniques. The following is a brief description of these new activities as well as a summary of major ongoing projects funded in FY 1989.

MANPOWER DEVELOPMENTA. National Leadership Institute on Aging

The National Leadership Institute on Aging, established in 1988 and located at the University of Colorado at Denver, is designed to enhance the leadership capacities of aging network executives and maximize their abilities to respond to the needs and opportunities of our aging society. During the first year, Institute activities were developmental in nature and included the establishment of a program philosophy and a conceptual framework for the project, as well as the development of curriculum, convening an advisory committee and other design and implementation tasks.

In its second year the Institute had numerous responsibilities to fulfill. These involved implementing four residential leadership development programs that were very successful. These residential seminars, the core of the Institute's program, are intended to assist aging network executives to examine and develop their leadership styles and capabilities and to challenge and inspire them to seek new ways to fulfill their roles as key policymakers in our rapidly expanding aging society. The success of these programs has been well documented and the Institute has achieved national recognition. Over 150 representatives of State Units on Aging, Area Agencies on Aging, national aging organizations, universities, and the private and non-profit sectors, from 48 States and territories, have attended Institute programs.

Other accomplishments over the past year included the refining of the leadership curriculum, the development of a cadre of Institute faculty, and the provision of consultation and technical assistance to the aging network. In addition, a substantive marketing campaign was undertaken to promote the Institute, including presentations at national conferences, news releases, and an article in Aging Network News. Brochures and program announcements were mailed to a wide audience, including all Area Agencies on Aging, Directors of State Unit on Aging and member organizations of the Leadership Council on Aging, as well as representatives of other national organizations.

B. Native American Leadership Institute

In FY 1988 a grant was awarded to Three Feathers Associates to conduct a training program for Title VI Directors. A 10

day intensive Training Institute was convened for 25 participants and received high evaluations. The curriculum included legislative and administrative history of aging services, program planning and implementation, program management and gerontology issues.

During FY 1989, Three Feathers Associates conducted a second leadership training program for 28 participants. In addition to the regular curriculum, a new component was added entitled "Federal Agency Implementation Process and Leadership Skills Development". In addition, participants received practical training in the development of a Program Management Information and Client Tracking System. Follow-up training and technical assistance was also provided.

C. Gerontological Faculty and Program Development

The Administration on Aging has continued to encourage the inclusion of aging content in programs that target professional and paraprofessional service providers, church and civic organizations, and faculty and student bodies in schools of higher education. These groups have significant influence on the lives of older persons and, therefore, benefit from specialized gerontological or geriatric content in their training and career preparation programs.

Ongoing Projects:

Eight grants were awarded in FY 1989 to institutions of higher education for gerontological training and development. These projects focused on key areas including faculty development in gerontology, replication of successful curricula in institutions where gerontology was not taught as extensively, and development of gerontological faculty and programs in minority institutions.

Examples include a project to provide gerontological training to faculty of 25 American Indian colleges; replication of successful gerontological social work curriculum in seven institutions in Hawaii and the Pacific Islands; and, development of gerontological programs in several New York institutions with high minority enrollments.

A FY 1988 grant was awarded to Gallaudet University in Washington, D.C. to develop a graduate level social work

curriculum in aging and hearing impairment. The project which ended in July 1990, produced a sequence of courses and field instruction for a specialization in gerontology and hearing impairment and produced a cadre of social workers who can provide direct services, participate in community planning and conduct research for the benefit of hearing impaired elderly.

New Projects: Faculty and Program Development

In FY 1990 there continued to be a focus on program development efforts to establish or enhance gerontological expertise of faculty in health and human service professional schools. Special emphasis was given but not limited to projects in institutions of higher education with predominantly minority enrollments. The nine new projects reflect a variety of creative approaches to faculty development in gerontology. Some examples include:

San Francisco State University (CA) will develop curricula and provide training in gerontology to faculty in community colleges. This project will potentially effect the education provided to 27% of the 1.2 million California community college students. The model multi-cultural curriculum, faculty training, and intern-mentorship program will be broadly applicable to other community college systems.

The Association of Schools and Colleges of Optometry (ASCO) (Maryland) will develop a competency based module, "Managing Low Income and Minority Elderly Patients" to be incorporated in their manual, Optometric Gerontology: A Resource Manual for Educators. In addition, ASCO will conduct two regional workshops for 100 clinicians and educators on the content and use of the manual.

Tougaloo College (Mississippi) will combine research, faculty development and information dissemination to improve the availability and quality of health promotion resources for the elderly in the State.

Florida A & M University plans to conduct a training program in geriatrics and gerontology for faculty from six Historically Black Colleges and Universities (HBCUs). The program will be a guide to faculty members on the formulation of gerontology curricula for existing educational programs and for new programs on aging for professional majors.

New Projects: Education to Prepare for an Aging Society

In FY 1990, AoA awarded grants to four national aging organizations and four universities to develop public education programs about aging for individuals and groups whose members hold leadership positions in such areas as business and labor, public administration and politics, media, professional and religious organizations and academia. The goal of these projects is to improve the public image of older persons and increase public awareness about the roles that American institutions can play to enhance the experience of aging today and in the future.

The National Association of Area Agencies on Aging (Washington, D.C.) will collaborate with the National Association of Counties to use the national network of Area Agencies on Aging to educate elected and appointed county officials. These officials will learn about national aging trends, their policy implications, and solutions that other localities have taken.

North Carolina Central University (Durham, NC) will conduct 11 workshops for State and local elected officials across the country, especially minority elected officials.

University of Mississippi Medical Center will work with the Southern Governor's Association to educate Governors and their staffs in 17 States. It is planned that each State will prepare an action plan for the 21st century that addresses the needs of the elderly.

The American Bar Association Fund for Justice and Education (Chicago, IL) will develop a film and accompanying materials designed to educate employers about the Age Discrimination in Employment Act. The goal of the project is to influence employer attitudes and perceptions about older adults and to encourage them to hire and retain older workers.

West Virginia University will conduct a statewide project to increase the clergy's knowledge about aging and aging resources in the local community. One outcome of the project will be to create a permanent linkage between the church and the Area Agencies on Aging.

The University of California at Los Angeles will provide education for television professionals, such as directors, writers and producers. The project will lead to more sensitive media portrayals of older adults and improved public perceptions of the elderly.

The American Society on Aging (San Francisco, CA) will develop a multifaceted public education program designed to challenge ageist stereotypes and recommend approaches for change by educating executives of professional and trade associations, unions, volunteer organizations and religious groups.

The National Council on the Aging (Washington, D.C.) will educate the members of 20 national civic, fraternal, denominational, and professional associations about the social and economic implications of an aging society and will encourage them to undertake initiatives in their communities.

D. Short Term Training

Twelve in-service and continuing education grants were ongoing in 1990. These were awarded to State Agencies on Aging, national aging and professional organizations, and academic institutions to develop and demonstrate non-academic credit instructional programs and materials for persons working with older persons. Occupational groups represented in these grants include nursing home nurses and aides, in-home aides, housing managers, speech pathologists, correctional and parole officers, residential care home operators and hospital discharge planners. Examples of projects include:

The American Speech-Hearing-Language Association is developing and disseminating an in-service training program for paraprofessional staff of residential care facilities on the communication disorders and needs of older persons.

Drexel University is developing and disseminating a training workshop and materials for State and county probation and parole agents to improve their capacity to counsel, advise and assist adjustment of elderly ex-offenders released from correctional facilities.

The Traveler's Center at the University of Connecticut at Storrs is developing a training and demonstration program linking aging service providers and housing complex managers to support frail elderly tenants.

Georgia State University has introduced behavioral science and aging content in courses at three Georgia seminaries resulting in certificates in gerontology in the ministry.

E. National Projects to Improve Accreditation Requirements in Aging

Four projects awarded in FY 1988 to national professional organizations were completed this year. These projects developed and refined instructional curricula and competency standards for those who work with older persons in the fields of social work, nursing, homemaker-home health care, physical therapy and counseling. Some of the products that emerged from these projects include a national certification process for testing and registration of homemakers and home health aides; curriculum models and resource manual for education and training physical therapists in aging; development of comprehensive competency standards for gerontological counselors and the acceptance of gerontological counseling as a recognized specialty in the counseling field.

TARGETTING - STRATEGIC RESOURCE ALLOCATION

A. Minority Management Traineeship Program

New Projects

In FY 1990 AoA funded six new projects designed to stimulate opportunities for training and employment of minorities for key management positions in the aging network. The program focuses on assisting highly motivated minority professionals, preferably with undergraduate or advanced degrees and several years of prior experience in the field of aging, to work in settings where they can serve as trainees in a management/administrative position. Three of the grantees are academic institutions, including an Historically Black College and University. Three of the grantees are minority aging organizations.

Boston College will provide full tuition in the School of Social Work for seven minority students. and place them in management positions in the aging network. Project will also include training of service providers through trainee initiated workshops on service delivery to minority older persons.

Hunter College of CUNY will provide tuition for 20 minority students in professional social work education. with focus on aging, management and minority issues. Project includes a mentoring system and a consumer advisory board.

North Carolina Central University will provide training toward a Masters in Public Administration with a gerontology focus to six current aging network employees and to seven graduate students currently enrolled in the MPA program. This is a collaborative effort of five North Carolina universities including two Historically Black Colleges and Universities, one Native American university and two non-minority universities.

National Caucus and Center on Black Aged will prepare seven Black trainees to pass the State licensure exams and to obtain permanent placement as long term care or nursing home administrators.

National Hispanic Council on Aging will place six Hispanic professionals in paid, 12 month management trainee positions in the office of the director of a variety of aging agencies. A "mentor" program is a significant component.

Asociacion Nacional Pro Personas Mayores will place six Hispanic graduates in paid, six month administrative level traineeships in public and private aging agencies.

Ongoing Projects - HBCU Initiative: Health Promotion Among Minorities

Ten projects were awarded under a FY 1989 initiative which utilizes the resources of Historically Black Colleges and Universities to focus on health promotion activities for older minority Americans. The HBCUs are developing educational materials and will train professionals to work with the minority elderly and conduct model programs to make health promotional efforts more accessible to older persons in need. Following are the institutions that are conducting projects under this initiative

- o Alcorn State University, Natchez, Mississippi
- o Florida A&M University, Tallahassee, Florida
- o Hampton University, Hampton, Virginia
- o Lincoln University, Jefferson City, Missouri
- o Morehouse School of Medicine, Atlanta, Georgia
- o Morgan Sate University, Baltimore, Maryland
- o Prairie View A&M University, Prairie View, Texas
- o Tougaloo College, Tougaloo, Mississippi
- o Virginia State University, Petersburg, Virginia
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PROMOTION AND ENHANCEMENT OF COMMUNITY BASED SERVICE SYSTEMSA. National Aging Resource Centers on Long Term Care - Ongoing Projects

Six national Aging Resource Centers on Long Term Care were established in FY88 for a three year period to provide training and technical information to State and Area Agencies on Aging to assist them in working with communities, public and private agencies, professionals and the public in implementing and coordinating programs and activities in a variety of topical areas. All six Centers were refunded during FY 1989 and 1990.

Each Center has a specific expertise in a field of long term care. These include case management and assessment, quality assurance, data collection and analysis, long term care management of Alzheimer's Disease Patients, Medicaid coordination, supply and training of home care personnel, and supportive services and arrangements in adult housing. Centers collect information and research results, produce issue papers, and provide consultations, training and technical assistance to State and Area Agencies in their chosen areas of emphasis.

The Centers and the Administration on Aging work jointly to develop work plans under the Centers' cooperative agreements. Each Center has conducted a needs assessment of State and Area Agencies in order to establish and prioritize its activities. The following is a brief description of each Center and its activities to date:

1. The National Aging Resource Center on Long Term Care - DECISIONS Center - at the Schools of Public Health and Public Administration, University of Minnesota, conducts activities related to community and in-home case management, with special attention to use of assessment instruments, patient and family preferences in selection of service options, professional ethics in decision making, planning and implementation of State case management systems, and use of Medicaid and Medicare waivers. The Center held two national invitational conferences - ethical issues in long-term care decision making and the use of assessment instruments - and facilitated planning and documentation of the Region IV Administration on Aging sponsored conference on long-term care. Publications and on-going work of the Center are published in a newsletter sent to more than 2,000 organizations and professionals in aging.

New publications released in FY 1990 included: Case Management in South Carolina: Review of Practices in the South Carolina Aging Network, Concepts in Case Management, Deciding Whether the Client Can Decide: Assessment of Decision-making Capability, Case Management: What is it Anyway?, and Meshing Services with Housing: Lessons From Adult Foster Care and Assisted Living in Oregon.

2. The National Aging Resource Center on Long Term Care - Alzheimer's Disease and Other Dementias - at the Suncoast Gerontology Center, University of South Florida, provides State Agencies on Aging with information, national and regional training sessions, and technical assistance to establish effective, comprehensive and coordinated statewide service systems and programs to recognize, diagnose, and provide short term treatment and long term management to Alzheimer's Disease patients, and to meet the needs of family caregivers. It serves as a bibliographic clearinghouse of publications and materials for State Agency on Aging planners and administrators. Information on new publications and the work of the Center is disseminated through a newsletter sent to aging organizations and professions, and selective health organizations performing research or supporting health care in the area of Alzheimer's Disease.

In FY 1990, the Center produced the following publications: Research Report on Dementia Specific Care Units, Caregiver Competence Paper, Resource Bibliography on Alzheimer's Disease, Ethnicity and Service Utilization, Minority Alzheimer's Caregivers: Removing Barriers to Community Services, Emergency Respite in Alzheimer's Disease, and Topics in Alzheimer's Disease: How to Establish an Alzheimer's Disease Registry.

3. The Heartland Center on Aging, Disability and Long Term Care - at the National Center for Senior Living in South Bend, Indiana, and the School of Public and Environmental Affairs, Indiana University at Indianapolis, provides technical assistance to meet the data needs and practices of State and Area Agencies on Aging in long term care planning and data analysis. Data-bases from surveys and studies which contain information pertinent to the need for provision of institutional, community and in-home services in areas of housing, health care, and social services are archived in the Center. Special emphasis is given to locating and profiling information on special populations - minorities, disabled, rural, urban, and suburban elders. Information on new publications and the work of the Center is disseminated through a newsletter sent to aging organizations and professional planners.

During FY 1990, the Center produced the following publications: Needs Assessments in the Aging Network: Guidelines and Best Practices, ADLs and Eligibility for Services: Implications for Minority Elders, AGEDATA Unmet Needs: The Challenge for Planning and Targeting of Resources, Aging in Black America: Service Needs and Utilization Patterns, The Graying of Black America: Selected Findings from the Longitudinal Study on Aging, The Survey of Income and Program Participation: SIPP As a Planning Tool for the Aging Network, The New Old: Aging in Hispanic America, The Unmet Needs of Caregivers: A Case Study in Three States, and Uses of the Annual Housing Survey for Studying Elderly Americans.

4. The National Aging Resource Center on Long Term Care at UCLA/USC - is a joint effort of the Multicampus Division of Geriatric Medicine and Gerontology at the University of California, Los Angeles, and the Andrus Gerontology Center at the University of Southern California. The Center's mission is to promote better health care partnerships among State and Area Agencies on Aging, hospitals and long term care facilities, decrease fragmentation and encourage more appropriate utilization by providers and consumers of the full range of options available to maximize the independence of older persons. The Center provides training and technical assistance in the areas of respite care, discharge planning, geriatric assessment, home modification and repair, and housing supportive services. It monitors programs and new activities at the State and national level affecting elderly housing and acute health care services. Each issue of its newsletter - distributed to more than 2,000 aging and health professionals and organizations is devoted to one of its mission areas. In FY 1990, the Center facilitated two national teleconferences on discharge planning and housing supportive services. It also facilitated an Administration on Aging Region I conference on housing.

Publications released by the Center during FY 1990 were: Discharge Planning: Training Projects to Enhance Continuity of Care, Home Modifications Resource Guide, Summary and Analysis of Administration on Aging Grant Awards in Home Modifications, Enhancing Continuity of Care: Model Practices Within the Aging Network, Respite Care: Lessons, Trends and Practices, Survey of State Unit on Aging Involvement in Discharge Planning Activities, Fact Sheet - Hospital Discharge Planning, Pending Federal Housing Legislation Affecting the Elderly, and Respite Guide: Running a Respite Care Program in the 1990's.

5. National Aging Resource Center in Long Term Care at Brandeis University provides training and technical assistance in a) community-based long term care; b) long term care public/private partnerships; and c) cultural diversity in the long term care workforce. During FY 1990 the Center coordinated 23 State and national training events; provided intensive technical assistance to 12 States; conducted cultural diversity focus groups and surveys in five cities; and, worked with the Administration on Aging to plan and implement the Commissioner's Meeting on Long Term Care.

Publications released by the Center in the fiscal year included: Emergency Issues in Long Term Care: Challenges for the Aging Network in the 1990's, Leadership Roles in Home Care Personnel Issues: A Challenge for State Units on Aging, and Strategies for Strengthening Long Term Care: Issues and Choices for the Aging Network.

B. Community Focal Points

In FY 1990 the Administration on Aging continued to support two earlier funded projects to encourage the development of senior centers as community focal points for older persons. The National Council on Aging (NCOA) prepared a focal point brochure for dissemination to the aging network, provided regional training for State and Area Agency on Aging staff on focal point designation and implementation, and began drafting a technical handbook for use by the network.

The Nebraska State Department on Aging demonstrated and evaluated a methodology for the development of community focal points in rural areas. It began work, in collaboration with NCOA, on a resource manual focused on focal point requirements in rural areas.

PREVENTION AND ALTERNATIVES TO INSTITUTIONAL CARE

During 1990 AoA conducted a wide range of activities that focus on enhancing the independence of older persons. Grants were awarded for projects to develop State long term care systems. In addition AoA continued the health promotion and disease prevention activities begun in prior years and funded some new projects designed to educate older persons about health promotion.

A. State Long Term Care Systems DevelopmentNew Projects

In FY 1990 nine grants were awarded to assist State Agencies on Aging develop collaborative efforts with other State Agencies, Area Agencies on Aging, and others to plan and implement specific improvements in State long term care systems. A variety of projects will be carried out over a two year period.

Older Alaskans Commission will carry out interagency planning efforts for "non-Medicaid" eligible populations to complement a Medicaid-only plan required by the State legislature.

Arizona Department of Economic Security/Aging and Adult Administration will demonstrate linkages of Older Americans Act and Medicaid systems in 13 rural counties.

Colorado Department of Social Services/Medical Services will link State aging, social service, Medicaid and vocational rehabilitation agencies to address Statewide case management practices.

Florida Department of Health and Rehabilitation Services/Aging and Adult Services will demonstrate the extent to which enhanced hospital based pre-admission screening and improved aging network and institutional linkages will affect community placements of older persons.

Hawaii Office on Aging will develop, in conjunction with key State agencies, Area Agencies on Aging and other segments of the aging network, a comprehensive long term care plan required by the State legislature.

Missouri Department of Social Services/Division on Aging will implement a comprehensive planning process in cooperation with Area Agencies on Aging and other State agencies.

Ohio Department on Aging will develop an interagency plan for home and community based care to provide a policy framework for recent "Eldercare" initiative approved by the State legislature.

West Virginia Commission on Aging will plan improved State longterm care system in cooperation with other key State agencies and Area Agencies on Aging.

Wisconsin Department of Health and Social Services/Bureau of Aging will demonstrate the extent to which more effective case management and improved linkages between community based and acute care providers will improve services for older persons.

B. Health Promotion

1. National Resource Center on Health Promotion and Aging

In October, 1988, AoA entered into a three year cooperative agreement with the American Association of Retired Persons (AARP) to establish a National Resource Center on Health Promotion and Aging. The principal mission of the National Resource Center on Health Promotion and Aging is to serve the State Units on Aging by providing training and technical assistance as well as providing information and other resources to agencies and organizations who are interested in health promotion and older adults. In 1989, the Resource Center continued to provide technical assistance to State Units on Aging, build its resource library and publish a bi-monthly newsletter which is distributed to 14,000 health and aging practitioners and other interested persons. In addition, the Center advertised a competition and selected nine States and one Region to receive intensive technical assistance on a specific activity or project; completed and disseminated a 45-minute video and brochure on minority health promotion models; worked with the five States in Region VI to develop a Region-wide smoking cessation strategy and with AoA and PHS to develop a national campaign for smoking cessation for older persons; assisted Region II to develop and conduct a regional conference on health promotion; began work with the nine other Regions to help them plan their regional conferences for 1991; developed a brochure about the 1990 funded health projects being conducted by ten Historically Black Colleges and Universities; developed a bibliography on minority health promotion projects; and, assisted and collaborated with the National Council on Patient Information and Education to disseminate resource materials on patient education in support of "Talk About Prescription Month" in October. AoA refunded the Resource Center in 1990 for a third year during which the Center will continue many of its current activities.

2. Prototype Health Promotion Projects

Ongoing Projects

The nine (9) self care projects funded in FY 1988 produced a variety of educational materials, models, and final reports. These projects, which were designed to produce prototype health promotion education models and campaigns, ranged from a public broadcasting television station developing a series of 300 programs on health and health promotion for seniors, to educating elderly Hispanics about the importance of various health promotion strategies.

The FY 1989 AoA Discretionary Funds Program Announcement, in keeping with Section 422(a)(2) of the 1987 Amendments of the Older Americans Act, encouraged institutions of higher education to submit applications for prototype health education and promotion programs. Nine (9) new projects totaling \$1,330,194 were funded and have focused on the following health promotion topics: nutrition education for Native Americans; injury prevention; smoking cessation; hearing impairment; physical fitness and exercise; and alcoholism. Most of these projects include the development and testing of prototype or model health education and health promotion programs which can be adapted or replicated by other States.

New Projects

Four projects were funded in FY 1990. These projects are designed to develop prototype models for educating older persons, their caregivers and families about hearing impairments, and promoting early intervention strategies for the prevention, detection and treatment of diabetes. The projects will be collaborative efforts among institutions of higher education, State Units on Aging, Area Agencies on Aging and appropriate other public and private agencies. The discretionary grants funded this year, as well as those funded in the last several years, will continue to help support AoA's substantial health promotion efforts:

University of Alabama at Birmingham - will train nutrition project staff to identify older persons with hearing problems and refer them for care. Project will target rural, low income, minority older persons.

University of Arizona - will develop a culturally appropriate health promotion program for Pascua Yaqui Indians with non-insulin dependent diabetes including therapeutic diabetic meals at senior centers and programs for exercise and weight reduction.

Boston University - will develop a statewide diabetes education initiative aimed at service providers and minority elderly to focus on etiology, symptoms, treatment and life style modifications.

Lincoln University of Missouri - will engage 10 Historically Black Colleges and Universities in a diabetic screening, referral and counseling program and a nationwide diabetes public education campaign.

3. Prevention of Fire and Smoke Related Injuries and Death

Americans over 65 years of age are three times more likely to die from fire than younger adults. To combat fire deaths and injuries among older Americans, the AoA funded four projects in 1988. These projects were designed to train providers, firefighters and the public to be more sensitive to the needs of older persons.

The three projects that concluded in FY 1989 focused on educating older persons and firefighters on the precautions to be observed to eliminate residential fire risks; rapid fire detection and suppression; and, how to increase escape chances. The fourth project, the University of Southern Maine, is continuing to work to develop a compilation of information about all the exemplary fire safety programs funded by AoA. The material will be incorporated into a program brochure and disseminated to the aging network.

4. Dental Health Promotion

In 1987 the AoA, recognizing the importance of oral health to the overall physical and mental wellbeing of older persons, funded nine dental health promotion projects. These projects, completed in FY 1990, focused on 1) providing pre-service and continuing education in geriatric dental and oral health care for dental and other health care personnel, and 2) promoting oral health care and good dental practice among older persons.

The University of Kentucky project "Oral Health Care Strategies for Family Caregivers in Appalachia" won the 1989 American Dental Association Geriatric Dental Health Care Award. The chief goal of this project was to utilize family caregivers to learn and apply strategies and interventions for oral health maintenance and to cope with oral problems of the homebound elderly with arthritis, stroke, Parkinson's Disease and Alzheimer's Disease.

C. Small Business Innovation Research Program (SBIR)

Under the Small Business Innovation Development Act (P.L. 97-219) DHHS and other Federal agencies set aside a specified portion of their research and development funds for an SBIR Program. The legislation is designed to stimulate technological innovation; use small business to meet Federal research and development needs; increase private sector commercialization of innovations derived from Federal research and development; and foster and encourage participation by minority and disadvantaged persons in technological innovation.

During FY 1990, AoA awarded three Phase I contracts under the SBIR program. These contracts address the applications of technology to meet the needs of older persons for devices which assist them to perform tasks of daily living. The specific products that will result from the 1990 awards are: 1) an affordable hygiene system designed for the disabled elderly to independently access and control of their personal hygiene safely and reliably; 2) construction of a unique air mattress for the prevention of decubiti and the enhancement of circulation; and 3) a detailed plan for educating professionals on the need for self help devices for the elderly.

D. Interagency Agreement on Technology and Aging

Another area in which AoA promoted use of technology as an alternative to institutional care is through its interagency collaboration with other Federal agencies with related concerns, resources and expertise. In 1985, AoA entered into an agreement with the National Aeronautics and Space Administration (NASA), the National Institute on Aging (NIA), the Veterans Administration (VA), and the National Institute on Disability and Rehabilitation Research (NIDRR). The purpose of this agreement is to collaborate on using NASA aerospace technology and scientific knowledge about aging to develop, produce and market devices to assist the elderly. As a result of this agreement, a prototype device to notify caregivers of wandering behavior by impaired older persons is being developed through a contract with Cortrex Electronics, Inc. The device will be adaptable to institutional or in-home use.

PUBLIC PRIVATE PARTNERSHIPS

A. Washington Business Group on Health

Ongoing Project

The Washington Business Group on Health (WBGH), a national membership organization representing over 200 business and health coalitions, is receiving support for a multifaceted project entitled "Partnerships In Aging". The project focuses on the development of model partnerships between

the business community and the aging network in a variety of areas including eldercare, work and retirement, and health promotion. WBGH provided small, seed grants for projects in eight localities that have now developed ongoing programs focused on caregiving, health promotion, counseling and other services for older persons and their families. Recently another round of small grants were made to another eight sites to develop additional business/aging network coalitions.

The project also develops conferences and forums focused on an aging workforce. In February, 1990, WBGH co-sponsored a conference on business and aging in San Francisco. Business representatives from all sections of the country made presentations describing their employers model programs in such areas as eldercare, older worker employment, and health promotion for retirees. In March the project co-sponsored a policy forum in Washington, D.C. on older worker employment and retirement transition programs. Special guests of the forum included Senator David Pryor and Senator John Heinz. WBGH, AoA, Senator John Glenn and Congresswoman Olympia Snowe co-sponsored a policy forum entitled "Corporate Health Promotion for Older Workers" in Washington, D.C. on June 25, 1990. The forum focused on identifying how corporate and community initiatives have begun to concentrate on the role of health promotion in improving the lives of older workers and retirees.

WBGH also produces a number of publications including a newsletter entitled "Together in Aging", as well as issue papers and training materials. The project is currently developing a series of guidebooks for human resource managers in three topic areas: eldercare; employment and retirement transition programs; and health promotion programs. The first of these reports, entitled "Working with the Business Community on Eldercare" is expected to be published this fall.

New Project

In FY 1990 the WBGH was awarded a grant to develop and disseminate training and technical assistance materials for the aging network on how to work with the private sector, particularly the business community. In addition to developing generic public private partnership training materials, actual partnerships will be developed in four sites across the country to demonstrate partnerships in specific program areas. Appropriate training materials will be developed at each site. WBGH will convene five bi-Regional conferences for aging network staff to provide them with public partnership training.

B. National Energy and Aging Consortium

The Consortium is a coalition of national public and private sector organizations concerned about the energy related needs of the elderly. Energy related needs are defined in the broadest terms to include such issues as housing, assistive devices in the home, and low income energy assistance. AoA continues to take an active role in the Consortium and serves as a member of the Steering Committee. A major focus of the Consortium is the development of State energy and aging consortia. To date, 14 such consortia have been established. In FY 1990 the Consortium will be working closely with the University of Oklahoma which was awarded an AoA grant to expand the energy and aging consortia network to other States.

C. Coming of Age in America

In FY 1990 AoA awarded a grant to Coming of Aging in America for the planning phase of a traveling exhibit which intends to educate Americans about aging and create attitudes and behaviors that will make America an exemplary society in which to grow old. The project is being developed in association with the Smithsonian Institution and the American Association of Retired Persons. The exhibit will visit shopping centers, museums and community centers in cities across the country. In addition, TV programs and newspaper supplements will take the message into almost every American home.

D. National Meals on Wheels Foundation

The National Association of Nutrition and Aging Services Program received an award in FY 1990 to develop private sector support to expand senior meals across the country. The project's primary thrust will be to assist local meals programs develop funds outside traditional Federal and State grants to meet the demands for service. NANASP will work to increase the involvement of corporate America, to encourage local charitable giving, increase public awareness and support, create national promotional events, support program innovations and provide professional training and technical assistance.

E. Eldercare: The Network's Response to the Needs of Employed Caregivers

In FY 1990 a grant was awarded to the National Association of Area Agencies on Aging to conduct a study of the extent and nature of services currently provided by the Aging

Network to assist employed caregivers of older persons. As the caregiving burdens on families has become more prevalent, its impact is being felt in the workplace. State and Area Agencies on Aging are being called upon with growing frequency by the business community to become involved in the development and implementation of services for their employed caregivers. The study findings will be useful in determining eldercare policy and program directions for the Aging Network.

STRENGTHENING THE FAMILY AND GENERATIONAL BONDING

It has been demonstrated that intergenerational programs represent a valuable resource to all participants, young and old alike. In FY 1990 AoA funded 22 projects with the goal of stimulating the replication of creative intergenerational programs. Twelve of the projects represent a range of programs conducted under a variety of auspices. Ten projects focus specifically on collaborative volunteer projects in Head Start Programs.

A. Model Intergenerational Projects

The twelve grants awarded in this area will develop models in areas such as intergenerational day care, services that address effects of the drug epidemic, training of child caregivers, assistance to older persons caring for grandchildren, services for pregnant and parenting teens and their children, and replication of successful projects in other communities. Some examples include:

National Council on the Aging - will conduct a program of information gathering and dissemination of model intergenerational child care programs in collaboration with Generations United.

University of Pittsburgh (Generations Together) - will conduct a project which highlights current intergenerational programs in three Pennsylvania communities (Harrisburg, Reading and Washington) and engages them as local resources to expand their models to new sites in the State.

Our Lady of Lourdes Associates Foundation - will develop LifeLinks, an intergenerational program aimed to encourage older adult participation as role models in the lives of teen parents and their children, a "Hug Me" program for infants deficient in nurturing, and a "Family Friend" support program for AIDS and other handicapped infants.

Aid to Imprisoned Mothers, Inc. - will focus on the complex plight of grandmothers who care for grandchildren during the mother's incarceration. The program will link resources from diverse agencies to strengthen the entire family.

B. Intergenerational Volunteer Projects in Head Start Programs

In FY 1990, AoA and the Office of Head Start (OHS), Administration for Children Youth and Families are jointly funding 10 two year model projects that will demonstrate ways that Head Start agencies and aging service organizations can work together to recruit, train and use the services of older adults in Head Start classroom and in-home activities. The anticipated benefits to the children and parents enrolled in Head Start include development and reinforcement of parenting and family management skills, intergenerational role modeling, tutorial education, and enhancement of self esteem through shared activities and experiences.

TITLE IV-B: RESEARCH AND DEMONSTRATION PROJECTS

Title IV-B of the Older Americans Act authorizes funding for research and demonstration projects to identify, assess and demonstrate new approaches and methods to improve the well-being and independence of older persons. AoA-supported research is focused on contemporary issues significant to the well-being of the older population and on linking advances in our knowledge of aging and the aging process to programs and policies responsive to the changing needs of older persons and their families. AoA-funded demonstration projects seek to test new models, systems and approaches for planning and organizing effective, comprehensive services delivery systems.

Several of the AoA National Goals constitute the organizing framework for describing AoA's research and demonstration initiatives in FY 1990. These goals are:

- o Public/Private Partnerships
- o Older Persons as a Resource
- o Strengthening the Family and Intergenerational Bonding
- o Prevention and Alternatives to Institutional Care
- o Promotion and Enhancement of Effective Community Based Service Systems
- o Targeting--Strategic Resource Allocation

New and continuing research and demonstration project activities carried out in FY 1990 are highlighted below. They are arrayed under each of the six (6) AoA national goals and grouped according to specific focus areas.

1. PUBLIC/PRIVATE PARTNERSHIPS

Developing Public/Private Sector Partnerships to Meet the Needs of Older People

New Project Activities: In FY 1990 AoA made thirteen (13) new awards to State and Area Agencies on Aging to generate new resources or to expand existing resources to meet the needs of older persons by supporting the development of new or expanded public/private partnerships. Three projects will expand resources for local senior employment and training programs. Four projects will generate new resources for aging support services programs within their

respective communities by establishing fund-raising non-profit corporations or business coalitions. Four projects will expand or initiate State or local eldercare programs at the worksite through provision of such services as adult daycare, counseling for caregivers, in-home care provided to frail elders by volunteers, and education for employees regarding aging. One project will demonstrate a countywide medication management system to ensure medication compliance by domiciliary residents and another project will expand health services for low income rural elderly living in isolated areas.

2. OLDER PERSONS AS A RESOURCE

Older Volunteers and In-Home Services for the Frail Elderly: AoA/ACTION Collaboration

New Project Activities: AoA and ACTION jointly awarded eleven (11) grants to support a three-year demonstration program to expand the use of Senior Companion volunteers in providing in-home services to the frail, homebound elderly. The program has the parallel objective of showing how public and private resources can be combined to support and sustain the work of Senior Companion Programs, leading toward establishing their self-sufficiency in the long term. Under each project, State Agencies on Aging, in collaboration with the appropriate Area Agencies on Aging and local Senior Companion Programs, have designated two Senior Companion projects as sites for the demonstration program. ACTION and AoA will cooperate in undertaking an evaluation of the program's effectiveness and applicability nationwide.

3. STRENGTHENING THE FAMILY AND INTERGENERATIONAL BONDING

Alzheimer's Disease Program Activities

New Project Activities: Under the FY 1990 Discretionary Funds Program, AoA made three (3) awards to help improve access to services by minority persons with Alzheimer's Disease and their family caregivers. Each project will address a different minority aging group to demonstrate innovative and effective ways to meet special information needs. Minority aging groups targeted are Blacks, Hispanics, and Asian/Pacific Islanders. Each grantee will demonstrate and evaluate what information channels and dissemination techniques are appropriate for reaching specific minority audiences.

Ongoing Project Activities: Under AoA continuation project awards, four (4) State Agencies on Aging increased their leadership capacity for making technical support and training available to those agencies in their States which serve Alzheimer's Disease victims and their families.

4. PREVENTION AND ALTERNATIVES TO INSTITUTIONAL CARE

A. Improving Services to Older Persons with Developmental Disabilities

New Project Activities: Increasingly, older persons with developmental disabilities (DD) are aging in place with their families. Consequently, the capacity of their older parents to continue as caregivers is under strain. Effective coordination and delivery of services to these individuals is urgently needed. To address these needs, four (4) grants were awarded for projects to be carried out jointly by State Agencies on Aging and State DD Planning Councils to develop aging/DD state and local planning linkages. The Administration on Developmental Disabilities (ADD) is co-funding three (3) of these projects.

These collaborative models will demonstrate and foster the replication of improved coordination and delivery of services to older persons with developmental disabilities and their aging parents. One State will produce and disseminate technical "how-to" manuals based on its experience of operating cross-network integration programs and assist other States with implementation. Another will establish: a centralized resource center for older persons with DD, their caregivers, and professionals; a caregivers' network and a protective services hotline; and an ongoing mechanism for statewide planning and collaboration. A third project focuses on: case-finding, identifying the unserved and underserved, particularly in rural areas of the State; targetting older American Indians with developmental disabilities; and on lifespan planning. The fourth project will address regulatory, program, budgetary, and other barriers to services, develop a core of 250 cross-trained personnel, and hold a national teleconference on aging and DD.

B. Quality Assurance for In-Home Supportive Services

Ongoing Project Activities: To demonstrate model quality assurance systems aimed at assuring higher standards of quality of in-home supportive services for

older people, AoA made awards, beginning in FY 1989, to eleven (11) State Agencies on Aging. Those projects were continued through FY 1990 and their findings were reported on in a conference in November 1990. Some salient elements of these models are: intermediate sanctions to address substandard providers; consumer education and consumer feedback; regulatory requirements, licensure/sanctions; use of long term care ombudsmen; use of volunteers as mediators; and self-advocacy.

5. PROMOTION AND ENHANCEMENT OF EFFECTIVE COMMUNITY BASED SERVICE SYSTEMS

A. Housing and Supportive Services

New Project Activities: The Administration on Aging funded nine (9) new projects in response to a growing awareness of the needs of the vulnerable elderly who are

aging in place in federally-assisted housing. These projects, funded for a two-year period, are designed to expand the availability of supportive services to moderate and low income frail elderly who reside in federally-supported facilities. The goal is to create a system which effectively links the service needs of the elderly with housing to permit independent living and avoid the need for changing housing arrangements or institutionalization. Five grants were made to State housing finance agencies, and four grants were made to State Agencies on Aging. Project activities will include:

- o development of statewide agreements between State Agencies on Aging and State housing, health and social services and finance agencies;
- o development of community plans between local housing authorities, health and social service agencies and local government to address service needs;
- o public education on the issues related to aging in place; and
- o technical assistance to the housing network and building managers on increasing the availability of supportive services, working with the elderly and their families, accessing community resources, and acquiring information about elderly residents on a regular basis to better assess their service needs.

B. Enhancement of Nutrition Services for Older Persons

New Project Activities: Three (3) grants were awarded to identify, develop, and disseminate innovative approaches for improving nutrition programs and services for the elderly. One project represents a collaboration between aging service providers and State Agencies on Aging aimed at reviewing and enhancing the operation of Title III nutrition programs. A second project focuses on generating private sector involvement and cost sharing in the nutrition services program. The third will conduct a feasibility study of a frozen/fresh meal system for serving isolated and homebound elderly.

C. Legal Assistance for Older Persons

New Project Activities: Legal assistance providers under Title III, to be effective, need the types of support available to other lawyers. AoA made grant awards to eight (8) national organizations to provide this support to State and Area Agencies on Aging, legal services developers, and legal assistance providers. These projects will help to make more effective legal assistance available to older people, especially those in the greatest economic and social need. Special emphasis is placed on the coordination of legal and other services provider under Title III. The grantees provide substantive case consultation and training in areas of the law of special importance to older persons.

Special Statewide Legal Hotlines Announcement:

AoA has, under a memorandum of understanding with the American Association of Retired Persons (AARP), begun a special initiative to expand the availability of Legal Hotlines for older people. In 1985 AoA funded a Title IV Demonstration by AARP in Pittsburgh, Pennsylvania to develop and test a Legal Hotline for Older People. This model worked effectively and was expanded to the entire State. Later, AARP with some AoA assistance provided seed money to develop hotlines in the District of Columbia, Florida, and Texas.

The current Legal Hotlines are receiving over 12,000 calls per year. When an older person with a legal problem calls the Hotline, specially-trained lawyers provide step-by-step advice on how to resolve the problem. Issues which cannot be resolved in one call are referred to local legal aid specialists or to a panel of attorneys in private practice who agree to

charge reduced fees. More than 81 percent of callers' legal questions can be resolved during the initial phone call, according to a 5 year evaluation of the existing Hotlines.

Under this new special initiative, five (5) additional Legal Hotlines are or will be receiving seed money, two from AARP (Ohio and Michigan were selected) and three from AoA. On July 6, 1990, AoA published in the Federal Register an announcement requesting preapplications for Statewide Legal Hotlines. Over 20 preapplications were received. AoA expects to fund the additional three Hotlines during FY 1991.

D. Information and Referral (I&R) Services

New Project Activities: I&R services are a major priority service for the national network on aging. For many individuals, I&R is the entry point into the services system which will allow them to find the assistance they need to remain independent and to be able to lead a life with dignity. To assist the aging network on aging in improving the quality and amount of I&R services available to older people and their caregivers, AoA has funded the following two (2) new grants:

- 1) "A National 800 Telephone Number for Locating Information and Referral Services of Area Agencies on Aging" - National Association of Area Agencies on Aging (NAAAAA)

This three-year project is designed to establish in stages a national 800 number through which callers can locate the name, address, and the information and referral telephone number for an Area Agency on Aging anywhere in the country. The expected results of this locator system include:

- o greater national recognition of existing community I&R systems through the national toll-free telephone number which will refer callers to local Area Agencies on Aging and/or their I&R providers;
- o a consistent and uniform identity for the aging network as a result of a public information campaign announcing the locator service; and

- o reduction of the difficulties faced by long-distance caregivers in linking their older parent(s) or relative(s) with appropriate supportive services.

NAAAA will make a major effort to develop financial support for the locator system from the private sector, especially corporate sponsorship.

- 2) "Enhancing the Capacity of State Aging Information and Referral Systems to Meet the Future Needs of an Aging Society" - National Association of State Units on Aging (NASUA)

This project will enhance the capacity of State aging I&R systems to meet the needs of a growing and increasingly diverse older population. Specifically, it will:

- o establish standards for I&R systems that are keyed to helping older people;
- o promote I&R systems improvement as a priority with the Aging Network;
- o facilitate the development of I&R systems improvement plans;
- o establish a national information exchange to provide access to existing I&R training materials, experts and best practices; and
- o provide training and technical assistance.

E. Community Based Systems of Care

Ongoing Project Activities: Under four (4) continuation grant awards, State Agencies on Aging are implementing models to build responsive community based systems for older persons. Each State agency is focusing on one or more unmet service needs particularly critical to the older population of the State. The effort at both the State and local levels focuses on collaboration with other State and local social service and health agencies. One State is developing models for community focal points in rural areas, while another is initiating programs to recruit, train, and retain long term care workers. A third project is focusing on the development of a community based adult day care program where currently no such program exists in the State. A fourth grantee is looking at solutions to the problem of broadening access to health care in a rural State.

Two (2) other continuation projects are demonstrating ways to promote more effective community based care to older persons. One project is seeking to determine the efficacy of using rural hospitals as community focal organizations working in conjunction with AAA's and senior centers to coordinate health and social services to older persons. The second project is demonstrating the efficacy of a state-wide health promotion campaign to prevent and treat diabetic retinopathy, particularly among high risk older populations.

6. TARGETTING - STRATEGIC RESOURCE ALLOCATION

A. Targeting Program Resources to Low Income Minority Elderly

New Project Activities: AoA awarded five (5) grants to National Minority Organizations and two (2) to local organizations to develop major outreach efforts to meet the problems of minority access to entitlement programs such as Supplementary Security Income (SSI), Medicaid, and Food Stamps. The goals of these projects are to increase awareness of entitlement programs among minority older persons and to enable them to gain greater access to supportive services and entitlement programs

B. Improved Targeting to Native American Elders

New Project Activities: In FY 1990 AoA made grant awards to three (3) Area Agencies on Aging, working in collaboration with Title VI Tribal organizations, to demonstrate new strategies to improve targetting of Federal, State, Tribal, and private resources to Native American elderly. One project will demonstrate a model service delivery system of case management and home care. A second project is developing an information and referral (I&R) program, with a needs assessment component, designed to provide better access to case management, chore, transportation and other services. The third project will demonstrate how to improve access to health and supportive services for Indian elderly through, 1) needs assessment, 2) advocacy and case management, and, 3) outreach through tribal governments and senior centers.

C. Alternatives To Guardianship

Ongoing Project Activities: Three (3) grantees continue project activities that are designed to encourage further development of alternatives to guardianship. One project is demonstrating in two states a model of early intervention services performed by trained volunteers. The model includes representative payee services, bill payer services, and development of self-help materials on money management. Another project is testing in three (3) states a national training module on guardianship alternatives and support services aimed at the aging network and a range of professionals, including social and legal services providers. Training sessions will be conducted this coming year in six (6) more states. A third project is expanding knowledge about guardianship by conducting a national survey of State practices related to the imposition and provision of guardianship services and the numbers and characteristics of adults affected by guardianship.

D. Developing Minority Elderly Agendas in National Organizations

Ongoing Project Activities: Seven (7) national aging and minority organizations continue, under AoA grant support, to develop or enhance their knowledge of minority aging issues and to broaden their capacity to deal with the concerns of low income minority elderly on an on-going basis. These organizations are engaged in the following activities: (1) creating a national network of Hispanic community-based groups committed to serving the elderly; (2) undertaking collaborative efforts between two national organizations, one of which serves the Black elderly, to develop local programs for the Black elderly using the resources of both organizations; (3) developing national support to expand research initiatives focused on issues concerning minority elderly; (4) supporting State Minority Task Forces through training and technical assistance; (5) encouraging national organizations representing components of State governments to address minority elderly issues; (6) training minority professionals to become leaders in the field of aging and; (7) supporting efforts to be responsive to the needs of elderly Pacific/Asians.

E. Studies on Alcohol Abuse and Alcoholism among the Aged

Ongoing Project Activities: Two (2) research grantees have received continuation project awards from AoA to analyze the incidence and prevalence of alcoholism among older persons. During the first year, a major part of the research efforts was focused on instrumentation and sampling techniques in preparation for the critical stages of data collection and analysis during the second project year.

F. National Aging Resource Center on Elder Abuse

Ongoing Project Activities: The National Aging Resource Center on Elder Abuse (NARCEA) is led by the American Public Welfare Association working in collaboration with the University of Delaware and the National Association of State Units on Aging. Established in FY 1989, NARCEA serves as a resource of information, data, and technical expertise on elder abuse to State and local aging and adult protective service personnel, to other professionals and practitioners concerned with elder abuse, and to the public.

The Center's technical assistance, training, dissemination, and short term research activities have focused on enhancement of knowledge and skills in elder abuse program development, agency management and service delivery, along with an increase in public awareness concerning the problem.

NARCEA provided training and technical assistance via teleconferences, conferences, publications, reports, articles in NARCEA EXCHANGE (the Center's quarterly newsletter), the information services of CANE (the Clearinghouse on Abuse and Neglect of the Elderly) and the NARCEA phoneline. In FY 1990, the Center conducted five teleconferences for State aging and adult protective services agency personnel on salient topics related to elder abuse. In addition, NARCEA convened a meeting of representatives of the Native American constituency groups to explore the problem of elder abuse within the American Indian communities. Proceedings of the meeting were published and disseminated to State and Federal agencies, tribal governments, and Title VI Program Directors.

NARCEA's principal mechanisms for information dissemination were NARCEA EXCHANGE, CANE, and the NARCEA phoneline. The newsletter was sent to 1,850 subscribers free of charge. The principal users of the CANE and NARCEA phoneline information services were State aging and adult protective services agencies, and service providers.

Short term research activities of NARCEA expanded in the second year. NARCEA called together a National Elder Abuse Research Panel, composed of nationally recognized experts, to draft a national research agenda. It is being refined and will be released next year. The research papers submitted by the panelists were compiled into "Elder Abuse and Neglect: A Synthesis of Research" and disseminated to State aging and adult protective service agencies. Other major research/technical assistance documents sent to the same audiences were "Summaries of National Elder Abuse Data: An Exploratory Study of State Statistics" and "NARCEA's Suggested Guidelines for Gathering and Reporting Domestic Elder Abuse Statistics for Compiling National Data."

NARCEA has and continues to work closely with the staff of the Long Term Care Ombudsman Resource Center on matters pertaining to the development of an AoA Elder Abuse Initiative and a Department Elder Abuse Strategy, both of which will address institutional and domestic elder abuse.

G. National Resource Center on Minority Aging Populations

Ongoing Project Activities: The National Resource Center on Minority Aging Populations was established in FY 1989 as a collaborative effort between San Diego State University and the University of Southern California. The Center was established to serve as a national focal point for technical assistance, training, information dissemination, and short-term research. Its efforts are supporting States, communities, educational institutions, professionals in the field, and the public in understanding and responding to issues affecting minority elderly.

In FY 1990, the Center continued to provide technical assistance to State Agencies on Aging via teleconferences, workshops and written materials. Two registries of resources for minority aging populations

were published as well as various bibliographies and mini-reports. Six issues of the Minority Aging Exchange Newsletter were disseminated. The Center held a three-day National Symposium on Minority Aging consisting of workshops related to economic well-being, social and human relations, and quality of life for minority elderly. Presentations will be published as a monograph. Collaboration with other national aging organizations continued during the second year.

H. National Resource Center for Rural Elderly

Ongoing Project Activities: The National Resource Center for Rural Elderly was established in FY 1989 at the University of Missouri at Kansas City. Its technical assistance, training, information dissemination, and short-term research and developmental efforts are supporting States, communities, educational institutions, professionals in the field and the public in understanding and responding to issues affecting the rural elderly.

The Center is serving as a national focal point for the identification of best-practice programs and services for the rural elderly in three primary focus areas (access/transportation, health/care coordination, and housing/assisted living alternatives.) The Center conducted workshops in the areas of access/transportation, needs assessment, housing alternatives, and caregiver support during FY 1990. The Center has also developed manuals on: rural transportation; needs assessment; barriers to coordination of services in rural areas; the developmentally disabled in rural areas; and adult day care. In addition, the Center has compiled a directory of model rural programs and updated the rural elderly bibliography, first published in 1989. These products have been or will be disseminated in early FY 1991. The Center is also publishing a bi-monthly newsletter entitled "The Rural Networker" and responding to ad hoc technical assistance requests from State Agencies on Aging on a variety of issues related to the rural elderly.

Another major activity of the Center has been the planning and cosponsorship of a national conference on rural elderly issues. This national conference will be held in Kansas City, Missouri in October 1990.

7. OTHER ADMINISTRATION ON AGING R&D ACTIVITIESA. Field-Initiated Research And Demonstrations

New Project Activities: Under the FY 1990 Discretionary Funds Program, AoA made several new awards to projects with the potential for making significant contributions to policy, planning, and improving services to the elderly. Each of these projects addresses important aging issues with national interest and implications that affect significant numbers of the aging population or especially vulnerable sub-groups. The projects cover such salient areas as: effective interventions to combat elder abuse; health promotion for older minority women; employment opportunities and recruitment in the field of aging and among older workers in general; energy and aging issues; and family caregiving and in-home care for the frail elderly.

SECTION V -EVALUATION

During this fiscal year the Administration on Aging started planning for a major evaluation of Title III-C-1 and Title III-C-2 of the Older Americans Act of 1965, as amended. The Elderly Nutrition Program (ENP) which delivers congregate and home delivered meals is the largest program expenditure (\$408 Million) funded by AoA.

The ENP has grown and changed considerably since it was last studied by AoA in 1982. The program now serves over 243 million meals annually to more than 3.5 million elderly participants. Because of the magnitude of the program, two years from the funding of the project (if resources are available) will be required to complete the study. The findings will be useful to the AoA, all State and Area Agencies on Aging, and all ENP providers for evaluating the efficacy of the program and developing guidance for future operations.

Administration on Aging

Long Term Care

AoA continued its support for long term care under Title IV-B of the Older Americans Act in 1990. The purpose of AoA's long term care activities is to develop a continuum of care ranging from prevention to maintaining maximum independence and self-sufficiency. AoA's long term care initiatives stem from a concern that chronically ill and functionally impaired older persons have access to appropriate community based care in order to prevent premature or unnecessary institutionalization.

In FY 1990 AoA awarded 11 third year continuations to the National Aging Resource Centers. Each Center is national in scope.

Six (6) of these Centers are pursuing the issue of the development of comprehensive, community based systems of long term care for older persons. Within the broad area of community based, long term care system development, each of these six (6) Centers focuses on one or more specific topical areas. The National Aging Resource Centers on Long Term Care are: Brandeis University, Bigel Institute for Health Policy, Waltham, MA; National Center for Senior Living, Heartland Center for Aging, South Bend, IN; University of California, Division of Geriatric Medicine, Los Angeles, CA; University of Minnesota, School of Public Health, Minnesota, MN; University of South Florida, Suncoast Gerontology Center, Tampa, FL and National Association of State Units on Aging, Washington, DC. In addition, AoA has funded the National Association of State Units on Aging to establish the National Long Term Care Ombudsman Resource Center.

Four (4) additional National Aging Resource Centers address other related, topical areas of vital concern in the continued development of comprehensive, responsive systems of services to meet the needs (including long term care needs) of older persons and their families.

In addition, AoA funded in FY 1990 grants to States to assist them in planning the development of long term care systems. Such projects would emphasize coordination among key agencies and Governor's offices in such planning.

Funding for long term care efforts are as follows

FY 1987	\$.2 million
FY 1988	1.6 million
FY 1989	2.9 million
FY 1990	2.8 million
FY 1991	~~1.2~~ million
	4.0 million
FY 1992	4.5 million

Public Health Service

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

AGING

The purpose of the Agency for Health Care Policy and Research (AHCPR) is to enhance the quality, appropriateness, and effectiveness of health care services and to improve access to that care. This is accomplished through the establishment of a broad base of scientific research and through the promotion of improvements in clinical practice and in the organization, financing, and delivery of health care services. The AHCPR also is responsible for facilitating the development, review, and updating of clinically relevant guidelines for specific conditions and treatments. As the focal point of Federal efforts in medical effectiveness and health services research, the AHCPR seeks to create and disseminate new knowledge and better understanding of the processes by which health services are made available and how they may be provided more efficiently and effectively.

The goal of the AHCPR health services research program in long term care and health services for the aging is to develop alternative strategies for providing care that will reduce Federal expenditures for these services, increase their availability, and improve their quality. In FY 1991-FY 1992, AHCPR will undertake and continue a number of initiatives to expand research on aging and long term care.

Medical Treatment Effectiveness/Outcomes Research

Studies supported by the Agency for Health Care Policy and Research show that there are often wide variations in the types of health care furnished to apparently similar populations within and across geographic areas. Of even more concern, the research also shows that often these variations are associated with different outcomes. The Medical Treatment Effectiveness Program (MEDTEP) of AHCPR has significance for saving and extending lives, improving the quality of health care for Medicare beneficiaries and other patients, increasing and maintaining patients' functional abilities, and conserving resources. These benefits can occur as a result of new investment in the development and dissemination of scientific knowledge about patient outcomes, allowing health care providers and their patients to make more informed decisions about treatment options.

Health services research in this country and elsewhere indicates that variations in the use of health care services and procedures reflect the complex interaction of clinical, social, environmental, economic, and psychological factors that shape the relationship between patient and provider. Variations are appropriate if they arise from differences in the needs and choices of individual patients, and if the alternative patterns of care are known to be equally effective and efficient. However, the "practice styles" of physicians account for many of

the differences observed in the care of patients with similar conditions, and providing physicians with information about the outcomes of care reduces these variations considerably. Practice styles are most variable for those health care conditions and procedures associated with greatest uncertainty and controversy among physicians. Research on patient outcomes and the dissemination of its findings will help to reduce these uncertainties and resolve these controversies.

FY 1990 marked a significant expansion in the AHCPR effort to develop reliable and comprehensive data on the effectiveness of different medical treatments. Eleven Patient Outcomes Research Team (PORT) projects were funded as part of MEDTEP through the Agency's Center for Medical Effectiveness Research (CMER). These projects are multiyear and multidisciplinary studies focused on variations in clinical practice and outcomes for a particular medical condition. Each PORT project is designed to identify and analyze the outcomes and costs of alternative practice patterns for a specific condition, determine the best strategy for treatment of clinical management, and develop and test methods for reducing inappropriate variations.

Ten of the eleven PORTs currently funded address clinical conditions that are common among (though not necessarily exclusive to) the elderly population. These projects are described below.

Richard A. Deyo, M.D., University of Washington, Seattle, WA
"Back Pain Outcome Assessment Team" Grant No. HS 06344

This PORT will assess alternative types of lumbar spine surgery (fusion, laminectomy, and discectomy), a variety of nonsurgical interventions (e.g., traction and various therapeutic injections), and diagnostic tests (including myelography, computed tomography, and magnetic resonance imaging, and thermography) commonly used for patients with back pain, especially pain due to spinal stenosis, the most common diagnosis leading to surgery among elderly patients. National and statewide hospital discharge data, Medicare claims data, and surveys of patients and physicians will be the basis for the formal decision analysis of the surgical decision that will incorporate probabilities, patient preferences for various health states, and costs. Findings will be disseminated via targeted feedback to physicians and hospitals in high use areas and by means of special materials for educating patients, whose decisionmaking role is especially important in these usually-elective procedures.

Back pain is a highly prevalent and expensive condition, ranked as the second leading cause for all physician visits. The costs, both for associated health care and disability compensation are high. Geographic variations in the use of hospitalization and surgery have been well documented, and the efficacy and effectiveness of some treatments have not.

Deborah A. Freund, Ph.D., M.P.H., Indiana University,
Indianapolis, IN "Assessing and Improving Outcomes: Total Knee
Replacements" Grant No. HS 06432

This PORT will determine and explain variations in rates and outcomes of total knee replacement (TKR) for patients with a diagnosis of rheumatoid or osteoarthritis. Researchers will construct and analyze a comprehensive decision model to aid physicians and patients in deciding whether to undertake TKR, and disseminate findings to physicians and patients, with the aim of reducing the wide variation that currently exists. Analysis will focus on areas of greatest controversy, as determined by a systematic synthesis of the literature and a survey of practicing physicians, regarding the relationships between outcome and practice variables. Comparisons of outcomes will be made between TKR and non-surgical treatment for patients presenting with different degrees of pain, disability, and co-morbidity. Outcomes will be assessed in terms of functional and symptomatic relief, clinical complications, costs, and associated patient utilities. The PORT will create the first comprehensive database for TKR, consisting of clinical and claims data from public (esp. Medicare) and private sources for the U.S., Indiana, Western Pennsylvania, and Ontario, Canada.

Progressive forms of arthritis are common, especially in the Medicare population which comprises about 70 percent of the estimated 175,000 total knee replacements performed in the U.S. in 1990. Rates of TKR are highly variable and appear to be increasing very rapidly despite the serious lack of information about the correlates of good outcome.

Barbara J. McNeil, M.D., Ph.D., Harvard Medical School, Boston, MA "The Consequences of Variation in Treatment for Acute Myocardial Infarction" Grant No. HS 06341

The PORT aims to establish a national center for the integration of information about medical technologies and processes of care for patients with acute myocardial infarction (MI). Four specific foci, selected based on meta-analyses and recommendations of a national advisory panel, include controversies surrounding: pre-discharge diagnostic tests for risk stratification (e.g., coronary angiography, exercise tolerance tests, echocardiography, Holter monitoring); acute interventions (esp. thrombolytic therapy, streptokinase, and percutaneous transluminal angioplasty (PTCA)); re-hospitalization within 3 to 6 months post-MI; and alternative procedures and medications used post-MI to reduce complications and recurrence (e.g., coronary arteriography, PTCA, aspirin, and cholesterol reducing drugs). Primary data will be obtained from an inception cohort of patients. Resource utilization, outcomes, and cost will be studied using Medicare data, plus comparable data from the Veterans Administration (VA). Recommendations will be developed and disseminated by means of direct physician education

and distribution of printed materials, in a series of interventions that target whole states, parts of states, and/or regions of the VA health care system.

Every year, at least 750,000 Americans suffer acute myocardial infarction. Medicare patients, who account for about 40 percent of these cases, have a cumulative mortality of 40 percent. Variations in treatment are well-documented and the relative benefits of numerous new treatments remain controversial, especially in elderly patients.

Earl P. Steinberg, M.D., Johns Hopkins University, Baltimore, MD
"Variations in Cataract Management: Patient and Economic Outcomes" Grant No. HS 06280

This PORT will assess variations in short-term and long-term outcomes and costs for treatment of cataracts. The analysis will include comparisons of the timing and type of surgical intervention (intracapsular cataract extraction, extracapsular extraction, and phacoemulsification), diagnostic procedures (including ultrasound and speculomicroscopy), and differences in follow-up care. Anticipated changes in demographic characteristics of the population over the next 25 years will be incorporated into the development of a model to project the clinical and economic impact of alternative strategies for the management of cataracts. Data will include Medicare enrollment and claims files, plus chart reviews and surveys of cataract patients and physicians in three sites. A panel of experts will define optimal management strategies for specified categories of cataract patients.

Cataract extraction is the single most common surgical procedure performed on Medicare beneficiaries. In addition to the economic burden associated with more than a million of these procedures each year, cataracts are associated with serious visual and functional impairment.

John E. Wennberg, M.D., M.P.H., Dartmouth Medical School, Hanover, NH
"Assessing Therapies for Benign Prostatic Hypertrophy and Localized Prostate Cancer" Grant No. HS 06336

A variety of surgical and nonsurgical interventions for benign prostatic hyperplasia (BPH) and localized adenocarcinoma (cancer) of the prostate will be assessed. For BPH, assessment will include variations in use and outcomes associated with transurethral resection, open prostatectomy, balloon dilation, bladder neck incision, transurethral incision of the prostate, prostatotomy, microwave diathermy, medical therapy, and "watchful waiting". For cancer of the prostate, early diagnostic screening, radiation, radical prostatectomy, and watchful waiting will be compared. Outcome variables emphasize the full range of outcomes that are relevant to patients, i.e., survival, morbidity, symptoms, self-assessed functional status and quality of life. Decision models based on probabilities of outcomes and

associated patient utilities will be developed and used to analyze the effectiveness and cost-effectiveness of treatment alternatives for subgroups of patients. Findings will be incorporated into materials produced to inform clinical decisionmaking, practice guidelines, research, and health care policy.

Enlargement of the prostate affects more than half of all men by the age of 80 years, and about 400,000 prostatectomies are performed in the U.S. every year. Uncertainty regarding both the natural history of prostate disease and the efficacy and effectiveness of alternative treatments has led to wide variations in practice.

David B. Pryor, M.D., Duke University Medical Center
"Outcome Assessment Program in Ischemic Heart Disease" Grant No. HS 06503

This PORT will identify inappropriate sources of variation in diagnostic and treatment strategies for chronic ischemic heart disease, (i.e., stable coronary artery disease) with the goal of maximizing health outcomes and efficient use of health resources. Alternative procedures to be studied include cardiac catheterization and revascularization with either coronary angioplasty (PTCA) or coronary artery bypass surgery (CABG). Analysis of patient outcomes and preferences regarding potential outcomes will help to define appropriate indications for these procedures. The project will also devise new approaches and methods for outcomes assessment, including integration of detailed clinical databases with claims databases. Patient-specific feedback and educational programs for regional groups of physicians will be employed to demonstrate the feasibility of affecting voluntary change in physician practice patterns.

Coronary artery disease remains the leading cause of death and a major cause of morbidity in the United States, leading to major clinical manifestations in one of every 3 men and one of every 10 women by the age of 60.

J. Sanford Schwartz, M.D., University of Pennsylvania **"Outcome Assessment of Patients with Biliary Tract Disease"** Grant No. HS 06481

This project will assess alternative procedures for the evaluation and management of patients with suspected or documented biliary tract (i.e., gallstone) disease. Outcomes will be compared for patients who receive alternative surgical procedures (esp. cholecystectomy), medical therapy, and no therapy. In addition, the use and value of alternative diagnostic tests (e.g., endoscopic retrograde cholangiopancreatography (ERCP) and intraoperative cholangiography) will be assessed. A combination of administrative and clinical databases, plus surveys of patients

and physicians will lead to assessment of outcomes and development of recommendations related to the quality and efficiency of care for biliary tract disease, both in hospitals and outpatient settings. Findings will be disseminated to physicians by their peers, in an intervention that permits comparisons across Pennsylvania communities. The impact will be measured in terms of changes in appropriateness of services, referral patterns, health outcomes, Medicare expenditures, and physician charges.

Although it affects an estimated 20 million Americans, and between 300,000 and 450,000 cholecystectomies are performed every year, gallbladder disease has received little attention.

James I. Hudson, M.D., University of Maryland "Analysis of Practices: Hip Fracture Repair and Osteoarthritis" Grant No. HS 06658

This PORT will assess the effectiveness of alternative management pathways for two closely related clinical conditions, hip fracture and total hip replacement for osteoarthritis. The analysis of variations in management and outcomes will focus on immediate surgery versus delay for stabilization and alternative types of surgical repair, and on the role of rehabilitation therapy, co-morbid conditions, hospital volume for these procedures, and length of stay. Probabilities will be estimated based on a retrospective analysis of secondary data from all Medicare patients in the State of Maryland who underwent hip fracture repair or hip replacement between 1984 and 1994, and a prospective analysis of primary data for patients undergoing hip fracture or total hip replacement in the same hospitals. The primary data will come from eight Maryland hospitals that account for the highest volume of procedures under study and one-fourth of all orthopedic surgeons in the State. The investigators will develop practice recommendations, disseminate them to physicians and the public, and measure the impact of these recommendations on practice patterns, patient outcomes, physician attitudes, and Medicare costs.

Among Americans over 65, more than 220,000 hip fractures are recorded annually. The burden of this condition is measurable in terms of disability, dysfunction, dependence, and death. Associated annual expenditures are estimated at \$7.3 billion. Total hip replacement has become a major mode of treatment for severe osteoarthritis.

Sheldon Greenfield, M.D., New England Medical Center "Variations in the Management and Outcomes of Diabetes" Grant No. HS 06665

The major objective of this PORT is to develop a comprehensive, prospective, longitudinal database tailored to the requirements of medical effectiveness in chronic disease, specifically Type II diabetes. Research on chronic diseases is complex because care extends over many years, patients use

multiple, mostly outpatient, providers and multiple types of health care resources, and quality of care depends heavily on interpersonal (e.g., educational, motivational) as well as technical aspects of care. The data system will be implemented in three large health care delivery organizations in Boston, Indianapolis, and Portland, where a total of approximately 6,000 patients will be enrolled and followed for four years. A combination of survey data, chart abstraction, and claims data will be linked for analysis of variations in practice, utilization, expenditures, and patient outcomes. Based on literature review, decision analysis, and analysis of the database, the PORT will develop practice recommendations regarding optimal technical and interpersonal care associated with the outcome of principal interest, patients' quality of life. Educational interventions, planned as randomized controlled trials, will aim to improve specific physician practices with respect to utilization, expenditures, technical and interpersonal quality of care.

Diabetes is a major source of health care costs and disease burden. The annual incidence of Type II diabetes is approximately 320 per 100,000 in persons over 20, and approximately 8,800 per 100,000 persons over 65 are affected. In 1982, diabetes accounted for 35,000 deaths and 5,800 new cases of blindness. It is associated with a high proportion of end-stage renal disease and non-traumatic amputations, as well as sharply increased risk of hypertension and ischemic heart disease.

Wishwa N. Kapoor, M.D., University of Pittsburgh "Assessment of the Variation and Outcomes of Pneumonia" Grant No. HS 06468

This PORT focuses on variations in the treatment of community-acquired pneumonia in adults, especially variations in rates of hospitalization, diagnostic, and therapeutic interventions (e.g. choice of antimicrobial agents). Two major aims are to evaluate geographic variation in hospitalization rates and to test the hypothesis that hospitalizations, ICU admissions, diagnostic tests, therapeutic maneuvers, and cost can be reduced without increasing morbidity or mortality. A comprehensive literature review will be undertaken, and variations in treatment and outcomes will be assessed using discharge rates and outcomes available in Medicare and other claims data for residents of Pennsylvania, Massachusetts, and Nova Scotia. This will be supplemented by a prospective cohort study of patients in Pittsburgh, Boston, and Halifax. The cohort will consist of approximately 2,500 patients accrued over 30 months and followed for 90 days, to obtain more detailed data about treatments and outcomes for ambulatory as well as hospitalized patients; a substudy of physicians will obtain detail about factors influencing clinical decisions. Economic analysis will consider both direct and indirect costs of care and comparisons across communities. Using decision analysis, cost effectiveness analysis and an advisory panel, the team will develop clinical recommendations. Educational interventions will

be implemented with the collaboration of the Pennsylvania Medical Society and Peer Review Organizations, and their impact will be evaluated.

Community-acquired pneumonia affects over 3,000,000 persons annually and is the sixth leading cause of death in the U.S. In the elderly population, pneumonia is particularly prevalent, dangerous, and costly. It is the fourth leading cause of death among persons over 65 and accounts for \$1.5 billion in Medicare inpatient expenditures.

MEDTEP Projects Pertinent to AGING - Non-PORTs

The AHCPR also supports grant and contract research under MEDTEP that typically is smaller and less complex. These projects focus on identifying or explaining practice variations, refining methods for effectiveness research, syntheses of information or meta-analyses, and data base development. These projects help to enhance the ability to assess different clinical approached and specific health conditions. In FY 1990, the Agency supported several MEDTEP non-PORT projects pertinent to aging:

Lee A. Green, M.D., University of Michigan "Diagnostic Uncertainty and Variation in the Use of Services" Grant No. HS 06409

The investigators will utilize medical records data for two Michigan communities to examine how the uncertainty of diagnostic indications contributes directly to the variations in admission rates for acute ischemic heart disease observed in clinical practice.

Lisa S. Meredith, The RAND Corporation, Santa Monica, CA. "Effects of Stressful Life Events on Health Outcomes" Grant No. HS 06622

This project is designed to study the effects of stressful life events upon health outcomes, particularly in the elderly and chronically ill.

Eleanor M. Perfetto, University of North Carolina "Variation in Physician Drug Prescribing in Rest Homes" Grant No. HS 06597

The objective of this research is to identify the source of variation in physician drug prescribing in a domiciliary care setting and how prescribing behavior affects resident outcome.

Enola K. Proctor, Ph.D., Washington University, St. Louis, MO "Adequacy of Home Care Plans for Chronically Ill Elderly" Grant No. HS 06406

This project will address the adequacy of home health care plans for the chronically ill through analysis of both the

planning and provision of formal and informal home health services. In addition to the development of patient-specific measures of care plan adequacy, the role of the cessation of Medicare payments, patient functioning, care plans, and various demographic, social, medical, financial, and service provider factors will be examined.

Arthur J. Hartz, M.D., Ph.D., Medical College of Wisconsin
"Equation-Based Severity Measures for Revascularization" Grant No. HS 06285

The investigators will develop and test the utility of a new measure of illness severity for patients undergoing coronary artery revascularization procedures. The measure may be used to identify high- versus and low-risk patients and to evaluate quality of care.

Mary E. Kerr, Case Western Reserve University **"CNNC & Outcomes in Cardiovascular Surgical Population"** Grant No. HS 06611

This project will examine the usefulness of a taxonomy of nursing diagnoses (Conditions that Necessitate Nursing Care, CNNC) in predicting selected patient outcomes following cardiovascular surgery.

Buell A. Miller, M.D., Maine Medical Assessment Foundation, Manchester **"The Hysterectomy Decision: Assessment of Outcomes"** Grant No. HS 06121

The purpose of this project is to reduce uncertainty about indications for hysterectomy by measuring health and quality of life outcomes for hysterectomy and alternative treatments for nonmalignant conditions.

William E. Neighbor, M.D., University of Washington **"Primary Care Lipid Practice and Policy in Hypertension"** Grant No. HS 06574

The study will examine primary care physicians' knowledge, attitudes, and clinical practice policies regarding the management of hypercholesterolemia in hypertensive patients and the extent to which these constructs are reflected in actual clinical practice. An educational intervention will be developed based on case policy feedback as a means of modifying physician practice behavior.

Roy M. Poses, M.D., Virginia Commonwealth University
"Predictions and Outcomes in Congestive Heart Failure" Grant No. HS 06274

Investigators will examine the ability of physicians' unaided predictions to distinguish between patients with congestive heart failure who do and do not need intensive care. Observational data from emergency room physicians will be

utilized and analyzed. Aggregated predictions will be compared with predictions of individual clinicians and examined against outcome.

Harry P. Selker, M.D., New England Medical Center "An MI Thrombolytic Therapy Outcome Predictive Instrument" Grant No. HS 06208

The purpose of this study is to develop a real-time predictive instrument (TPI or thrombolytic therapy predictive instrument) to determine which patients in the emergency room setting are most likely to benefit from thrombolytic therapy.

Theodore G. Ganiats, University of California, San Diego "Cost/Utility of Stroke Prevention" Grant No. HS 06098

This project supplements ongoing NIH studies on the effectiveness of alternative approaches to two major risk factors for stroke, i.e., asymptomatic carotid atherosclerosis and nonvalvular atrial fibrillation. Benefit/cost/utility data will be obtained from patients participating in the multicenter NIH studies in order to improve clinical decisionmaking.

Ty Hartwell, Research Triangle Institute "Community Health Care Models for Diabetes Prevention and Control Intraagency Agreement #AHCPR 90-16 (with CDC)

This project seeks to establish whether health care and health promotion activities that are thought to be efficacious in diabetes prevention and control are in fact effective in preventing morbidity and mortality, especially in communities with large minority populations.

Laurence F. McMahon, Jr., M.D., University of Michigan "Evaluation of Clinical Outcomes in Small Areas of Michigan" Grant No. HS 06486

This study will examine small area variations in performance of cholecystectomy in Michigan to determine correlations with demographic, clinical, and socioeconomic variables. Generalizability of the results will be assessed by comparing local variability with that found nationally, using Medicare data.

Helene L. Lipton, Ph.D., University of California, San Francisco "Detection and Origins of Geriatric Drug-Related Hospitalizations" Grant No. HS 06443

This project will develop a protocol to identify and characterize geriatric drug-related hospitalizations and the associated physician prescribing practices and patient compliance factors.

George A. Diamond, M.D., Cedars-Sinai Medical Center, Los Angeles, CA "CorSage--A Hybrid System for Myocardial Infarction" Grant No. HS 06065

This project will develop and evaluate a computer aided system for generating or critiquing plans for management of patients with ischemic heart disease. The system combines statistical (clinical data base) and heuristic reasoning (information from clinical cardiologists) in the patient management process.

William A. Knaus, M.D., George Washington University "National Program to Improve the Quality of ICU Services" Grant No. HS 05787

The purpose of this study is to develop a well understood measure of severity of illness for patients in the intensive care unit. This project addresses the issues of how to effectively and efficiently use high technology critical care resources and how to allocate them rationally on the basis of expected benefit.

Frederick Mosteller, Ph.D., Harvard School of Public Health "Meta-Analysis for Medicine: Application and Methods" Grant No. HS 05936

Meta-analysis is a method for combining the results of multiple studies in order to increase the statistical and scientific credibility of the individual results. This project will carry out new meta-analyses and update previous meta-analyses for certain diagnostic and therapeutic procedures, thus contributing both to knowledge of the effectiveness of procedures and to methods for future evaluations.

John E. Wennberg, M.D., MPH, Dartmouth College "Evaluating Outcomes of Hospital Care Using Claims Data" Grant No. HS 05745

This project will evaluate the utility of claims data from Medicare and from the Manitoba Health Commission for the evaluation of outcomes associated with selected surgical procedures and medical admissions.

Development/Updating of Clinical Guidelines, Quality Standards, Performance Measures, Medical Review Criteria

The AHCPR promotes the quality, appropriateness, and effectiveness of health care by facilitating the development, review, and updating of clinically relevant guidelines for specific conditions through the office of the Forum for Quality and Effectiveness in Health Care. Health care providers, educators and consumers will use these guidelines to help determine how to prevent, diagnose, treat and manage health conditions most effectively. The Agency also assists in the

creation and periodic updating of quality standards, performance measures and medical review criteria that may be used to assess and help ensure the quality of health care. Under P.L. 101-239, two mechanisms may be used to accomplish these: (1) panels of qualified experts and health care consumers can be convened, and (2) contracts can be issued to public and non-profit private organizations. AHCPR elected to utilize the panel process for developing the initial seven guidelines in FY 1990 and 1991.

The priorities of clinical conditions to be studied are identified in conjunction with the Institute of Medicine, the Health Care Financing Administration and professional organizations. Criteria for the selection of conditions include:

- specific needs of the Medicare and Medicaid populations;
- expected potential for reducing inappropriate variations in the prevention, diagnosis, management or outcome of a particular condition;
- number of individuals affected by the clinical condition;
- cost of the condition to all payers including patients; and
- adequacy of scientific evidence to develop guidelines and standards, etc.

Of the initial seven clinical guidelines being developed, four affect large numbers of elderly: benign prostatic hyperplasia, cataracts, urinary incontinence and the prevention and management of pressure sores. The remaining three are also of importance to the elderly as well as to many of the general population: pain management, sickle cell disease and depression among outpatients in primary care settings. These guidelines will be completed in FY 1991 and early FY 1992. The development of standards of care, performance measures and medical review criteria will follow in FY 1992 when the clinical guidelines for the elderly are completed.

General Health Services Extramural Research

The AHCPR's Center for General Health Services Extramural Research supports peer-reviewed grants and contracts conducted at universities, at nonprofit organizations and institutions such as teaching hospitals, and by industry. In Fiscal Year 1990, a number of general health services extramural research projects were supported on issues related to developments in aging, the elderly and long term care.

Projects Completed in FY 1990:

"Variations in Patterns of Primary Care Among the Elderly"
 Charlyn Black, M.D., Sc.D., The Johns Hopkins University,
 (Dissertation), Grant No. HS 06099

A population-based approach was used (1) to develop measures of primary care from routinely collected administrative data and (2) to examine factors associated with variation in patterns of ambulatory care at the population level. The study used secondary analysis of linked survey and claims utilization data for a representative sample of elderly individuals in Manitoba, Canada. Two measures of primary care were developed: a measure of longitudinality (the degree to which a single physician is used when an individual seeks medical care) and a measure of comprehensiveness (the extent to which an individual receives a complete set of services). The results suggest that the distribution of longitudinality and comprehensiveness in the population is not random. Variation in these patterns of ambulatory care appears to be related both to personal characteristics of patients and to the primary care orientation of the medical care they receive, such as the generalist/specialist orientation of services. This study has demonstrated the usefulness of a population-based approach to measurement of primary care and has developed measures that have applications beyond the scope of this research.

"The Use of Medical Services and the Decision to Retire"
 Charlotte Muller, Ph.D., Research Foundation, CUNY, Grant No. HS 05729

This project tested the relationship between health and the retirement decision. The following findings were reported: retirees who report work-limiting problems do not use health as an excuse for retiring early; the probability of dying within two years after retiring and the probability of seeking medical care are much higher for all retirees who report work-limiting health reasons. The study's findings are more pronounced for early retirees (before age 65) than for later retirees (retiring at 65 or older.) The study also found that men retiring with health problems tended to be poorer, have less education and were more likely to have worked in physically demanding occupations compared to those who did not report health problems upon retirement. The results of this study were published in Health Services Research in the June 1990 issue. Also the AHCPR Research Activities issue of August 1990 discussed the findings.

"Case Control Study of Users and Non-Users of Home Health Care"
 David Rabin, M.D., Georgetown University, Grant No. HS 06049

Cross-sectional analyses of all 4235 ADL/IADL (Activities of Daily Living/Instrumental Activities of Daily Living) impaired respondents, age 60+ in the 1984 National Health Interview Survey on Aging revealed that certain ADL/IADL limitations were most

strongly associated with Home Health Care use. Those with ADL needs were more likely to be Home Health Care users than Other Community Service users or Non-Community Service users. Among impaired elderly receiving help, IADL users were more likely to receive paid help. Additionally, home health care users were more likely to be female, in poor health, unmarried, or have low income. A case control study of the 418 Home Health Care users matched by age and sex to Other Community Service users and Non-Community Service users showed that Home Health Care users were in poorer health, and were more likely to live with others and have higher incomes. Every ADL and IADL limitation was more common in Home Health Care users than in controls. Multiple regression analyses revealed selected ADLs and IADLs to be the most significant functional status predictors of Home Health Care use. In summary, while functional status, appropriately, is the strongest predictor of Home Health Care use, socio-demographic factors also predict Home Health Care use among the elderly.

Projects Ongoing in Fiscal Year 1990:

"Impact of Toileting Dependence on Home Health Charges" Dorothy J. Baker, Yale University, Grant No. HS 06291

This dissertation research grant will retrospectively examine data already collected on a cohort of 8,000 low income elderly persons in the state of Connecticut receiving home care through a special program (Promotion of Independent Living) administered by the state's Department on Aging during the period 1982-1986. This study is expected to make unique contributions to the currently rather sparse literature on determinants of use and costs of home care. The special emphasis on examining dependence in toileting is warranted by the special burdens it places on patients and on informal and formal caregivers. Despite growing recognition of the importance of this particular set of problems, previous research has only indirectly estimated its cost implications. Moreover, most evidence is based on the experience of populations residing in nursing homes. This unique data set and the results of the analyses will provide valuable insights that may influence home care policy and may help to motivate further clinical research addressing the problem of incontinence.

"Home Health and Nursing Home Market Analysis" Charlene Harrington, University of California at San Francisco Grant No. HS 06174

Secondary data from Medicare and Medicaid and other sources and primary data to be collected on state policies and bed supply for the period 1986-1988 will be used for this study. By building upon previous HCFA and NCHSR studies, the project will develop a ten-year cross-sectional time series data base of both secondary and primary data for 1978-88. Differences within the ten-year time period will be examined. This study will produce papers designed for policymakers to consider in making changes in

Medicare and Medicaid program policies. The descriptive analysis will provide valuable new primary data on state Medicaid nursing home and home health reimbursement rates and methods and total state nursing home bed supply not available from other sources. This study will examine the trends in state spending during the ten-year time period, and examine differences in pre- and post-Omnibus Budget Reconciliation Act of 1981 (OBRA) and pre- and post-DRG periods. The analyses will develop a better understanding of the market forces, which is said to be needed by researchers, industry officials, and policymakers.

"Urban/Rural Differences in Elderly Use of Long-Term Care"

Dr. Charles McConnel, University of Texas Southwestern Medical Center, Grant No. HS 06197

Dr. McConnel will establish the extent and determinants of differences in survival and utilization of health and community based services by the rural/urban elderly. Data from the Longitudinal Study of Aging, the Census of the Population, the National Death Index, and the Health Professionals Resource File will be linked. A single analysis will then link a defined population data by health status, health services access, and health services utilization. The outcome variables include: physician visits, nursing home admissions, home health and/or nursing visits, homemaker services, use of community services and hospitalization.

"Functionally-Limited Elderly Living Alone: Access to Help"

Charlotte F. Muller, Ph.D., Research Foundation, CUNY, Grant No. HS 06030

This study examines whether disabled elderly living alone differ in the availability of informal care, functional limitations and economic resources from elderly living with others. Additional research questions include not only the effect of caregiving on women's employment, but also the effect of employment on the amount of time given to informal care. Data sources include the 1982 and 1984 national Long Term Care Survey. Preliminary findings indicate full-time employment substantially decreases the time allocated to informal care. Information from this study will aid in strengthening public policies aimed at maintaining the disabled in the community.

"Effects of Advance Directives in Medical Care"

Lawrence Schneiderman, M.D., University of California at San Diego, Grant No. HS 05617

The effects of an advance directive will be determined by a longitudinal, randomized experiment of 100 experimental and 100 control subjects all of whom have life-threatening illnesses. The experimental subjects are being offered the opportunity to execute an advance directive by their physicians; the controls do not receive an offer. All subjects are measured to determine levels of satisfaction, health status, health locus of control,

utilization of health services and costs of care at intake, three months, six months, one year and tow years. Analyses will be carried out within the context of the General Health Policy model. The study is expected to show that an advance directive will increase patient satisfaction and control, have no effect on patient's health status, and decrease cost by not using expensive life-sustaining forms of care that it is believed can have no demonstrable effect on patient health for a specific subset of terminally ill patients.

"Living Wills for Primary Care, AIDS, and Cancer Patients"

John D. Stoeckle, Massachusetts General Hospital, Grant No. HS 06120

The objective is to assess whether comprehensive living wills are practical and desired by physicians and patients, and to provide some models for how they can handle the process of indicating preferences for care, and develop a model for living will format. The specific goals of this proposal are: (1) to improve the format of available predrafted living wills by allowing individuals to specify preferences based on several hypothetical scenarios (2) to assess patients' interest in discussing terminal care issues, as well as their perceptions of barriers to such discussion; (3) to assess the extent to which patients have, and wish to have, living wills; (4) to assess how durable (reliable) patients' preferences are; and (5) to measure any changes inpatients' attitude regarding living wills as a consequence of participating in the survey (by self-report).

"Measurement of Preferences for Life-Sustaining Treatment"

Richard F. Uhlmann, University of Washington, Grant No. HS 06343

The objective of this project is to measure the validity and reliability of patient preferences for life-sustaining treatment and states near to or worse than death, to identify the medical interventions, and health and social states which form the domain of content for advance directives, as well as the factors which influence their acceptability. Results will be directly applicable to the development of valid, efficacious, and effective advance care directives. In addition, they will provide an improved basis for understanding the validity and reliability of preferences contained in advance directives.

New Starts in Fiscal Year 1990:

"Use of Health & Social Services by Older U.S. Hispanics,"

Ana I. Alfaro-Correa, Johns Hopkins University, Grant No. HS 06603

This dissertation research will evaluate the relationship between sociodemographic and health characteristics and use of health services among elderly Hispanics. Secondary analyses will be performed on data collected from a national telephone survey of noninstitutionalized elderly Hispanics conducted in 1988. The

outcome measures will include: use of health services only; use of social services only; use of both health and social services; and use of neither type of service. Comparisons among and between the four subgroups represented in the sample will be performed. This research is expected to help explicate the utilization patterns of the elderly Hispanic population and could be useful for policy analysis in the area of organization and delivery of health services for the minority aged in the U.S.

"Factors Influencing the Use of Medicare's SNF Benefit"

Lynn A. Blewett, University of Minnesota, Grant No. HS 06604
(Dissertation)

This study will examine the influence of patient and hospital characteristics on the use of Medicare post-acute care by Medicare beneficiaries. The research also will describe the nursing home's role in determining Medicare eligibility for Medicare's Skilled Nursing Facility (SNF) benefit. The analysis will use data from a national study of Medicare post-acute care use by Medicare beneficiaries in three urban areas: Minneapolis, Houston, and Pittsburgh. Data from a random sample of 2,687 Medicare beneficiaries in five DRG categories will be used to analyze the influence of patient and hospital specific characteristics on the use of post-acute SNF services. The expected findings should provide valuable information on differences in patterns of use and access to the Medicare SNF benefit. This study will also contribute to the understanding of the bundling of Medicare post-acute care payments with hospital inpatient payment. The findings on the role of the nursing home in determining Medicare eligibility will provide increased understanding of factors determining eligibility to the Medicare SNF benefit.

"Making Choices and Allocating Resources Near Life's End"

Marion Danis, M.D., University of North Carolina at Chapel Hill, Grant No. HS 06655

Two groups of subjects will be involved in this prospective cohort study: (1) hospitalized elderly patients who have either severe chronic lung disease, severe heart disease, or metastatic cancer and (2) physicians of these patients. The patient population included in this study is extremely sick, so that it cannot be assumed that the preferences of this group regarding life-sustaining treatments reflect those of other elderly individuals who are less severely ill. Their illness is severe enough that it is expected to impact upon the patients' quality of life.

In prior work by the principal investigator, quality of life did not predict willingness to receive life-sustaining intensive care. The intention in the current proposal is to study individuals with more severe chronic illness than studied previously and to re-examine the relationship of quality of life and preferences for life-sustaining treatments under these

circumstances. It is hypothesized that elderly individuals who are less severely ill have more energy to devote to closure of their lives and are less likely to face premature death and hence they might be less inclined to use life-sustaining treatments. That group of patients being sampled currently will serve as a comparison group, and will allow testing this hypothesis.

"HMOs and the Elderly: Adjusting Medicare Capitation Rates"
Kathryn Hyer, (Individual Grantee), Grant No. HS 06768

This dissertation grant will examine whether the inclusion of measures of self-reported health status can improve the efficiency and effectiveness of the payment formulas used to determine capitation rates for Medicare beneficiaries enrolling in health maintenance organizations. It is expected to produce an empirical model for predicting annual health care utilization for individual Medicare beneficiaries enrolled in HMOs, based on self-reported health status and demographic characteristics.

"Effects of Stressful Life Events on Health Outcomes" Lisa Meredith, The RAND Corporation, Grant No. HS 06622 (Dissertation)

This project will develop operational measures of stressful life events and look for relationships between these measures and specific aspects of health of elderly patients with hypertension, diabetes, coronary heart disease and depression. The data used will be from the Medical Outcomes Study. Findings will describe the effects of such life events as bereavement, work changes, and changes in family structure upon the physical and mental health and social role functioning of the chronically ill elderly.

"Payment Sources for Elderly Nursing Home Residents" Vincent Mor, Ph.D., Brown University, Grant No. HS 06233

This study analyzes longitudinally sources of payment used by individuals in the course of an episode of care in the nursing home. Other research questions estimate multivariate models of the conversion of Medicaid and models the rate of transitions among payment sources. Administrative, financial and patient assessment information from 43 facilities in the National Health Corporation (NHC) chain of nursing homes are the primary data source. NHC facilities in Kentucky, Missouri, Tennessee, and South Carolina will be included. Data will be drawn from a cohort of new admissions for 1982, 1984, and 1986, each of which will be followed for two years. Survival models will be used to examine conversion to Medicaid. Event history analysis will be used to model transitions of patients between payment sources over time. The dependent variable is the source of payment; independent variables include sociodemographic characteristics and functioning level. The study will provide a more complete picture of the transition to spend down since it includes data on public and private payment sources.

"Living in the Community or Leaving it for a Long Nursing Home Stay" Charlotte Muller, Ph.D., City University of New York, Grant No. HS 06672

This study examines what factors lead to nursing home stays of differing lengths with emphasis on long-stay nursing home patients. It also compares and contrasts long-stay nursing home patients with those who remain in the community. The research will use hazard functions to estimate the risk factors of a long stay in a nursing home. Multinomial logic models will be used to estimate the determinants of living in a community or residing in a nursing home. Data sources are the 1982 and 1984 National Long Term Care Survey and the linked Medicare (Part A) file. Dependent variables are community residence, short nursing home stay and long nursing home stay from the 1984 NLTCs. Explanatory variables include functional status, health status, hospital stays, informal care, income, race and utilization variables.

"Affect of Excess Demand on Medicaid Use of Nursing Homes" John A. Nyman, Ph.D., University of Minnesota, Grant No. HS 06193

The analysis recognizes the importance of integrating excess demand for nursing home beds into the analysis of Medicaid utilization of nursing homes. The study hypothesizes that under excess demand conditions, Medicaid utilization of nursing homes will be determined by private utilization. The study will estimate three different utilization equations--total, private, and Medicaid using data from Wisconsin, Minnesota, and Oregon. The investigator will test whether Medicaid utilization of nursing home care reflects the unconstrained behavior of Medicaid patients or whether Medicaid utilization is really driven by the determinants of private utilization under conditions of excess demand and payment rates that favor private patient admissions. Access to nursing homes by the elderly, especially those who are poor and receive Medicaid, is a relevant concern at the state and federal levels and in an aging U.S. population.

General Health Services Intramural Research

The aging of the U.S. population has heightened public and private focus on the health, social, and residential services required by individuals who have lost the ability to function independently because of ill health and physical and mental impairments. The increasing risk with age of incurring such impairments, coupled with the rapid growth of the elderly, will ensure that caring for the impaired elderly will continue to be an important issue for public and private policies.

The AHCPR's Center for General Health Services Intramural Research directly undertakes health policy research and analysis in three major areas: national health care expenditures and utilization, hospital costs and utilization, and long-term care. The Center also provides technical assistance to other agencies of the Government and to other public and private organizations

involved in financing or delivering health care. Staff of the intramural research Center have been involved in research on the problems of financing long term care for a number of years. In addition, staff are conducting research on health, social, and residential services for physically and mentally impaired elderly.

Long-Term Care Data

Using such large data sets as the 1982 and 1984 National Long Term Care Surveys, the 1982 Informal Care Giver Survey, and the 1985 Nursing Home Survey, the AHCPR's intramural research program on Long Term Care undertakes studies on problems such as long-term care expenditures; the feasibility of alternative financing and reimbursement strategies; and the types of care that might be required for particular levels of functional disability.

National Medical Expenditure Survey (NMES)

In FY 1990, work on the 1987 National Medical Expenditure Survey (NMES) continued. This survey provides a unique data base on how the population uses health care, what they pay for this care, and how we finance these expenditures. A substantial amount of new information on the elderly and long term care has been collected. The national household survey of the civilian noninstitutionalized population includes an oversampling of groups of particular policy interest, including the elderly. In addition to the core data on use, expenditures, health insurance, and sociodemographic variables collected for the noninstitutionalized population, the 1987 NMES household survey has a new focus on long term care. For example, data are being obtained on charges and sources of payment for both formal and informal caregivers and on various measures of health status and functional limitations of the noninstitutionalized long term care population.

The NMES provides a unique opportunity to examine the utilization and expenditures for long term care provided in the community and in institutions. To permit estimates of the utilization and expenditures associated with community based care, the Household Survey Component (HHS) of NMES was designed to include an oversample of elderly and functionally impaired individuals. Approximately 6,000 elderly and 13,000 functionally impaired elderly are included in the data. A parallel survey was conducted among 10,000 residents of nursing homes and homes for the mentally retarded. In both surveys, respondents were followed as they entered and were discharged from institutions.

The following bibliography reflects aging-related papers/publications completed by staff of the Center for General Health Services Intramural Research in FY 1990:

- Authors: Jackson, Mary E., Spector, William and Buffum, Henry
 Title: Resident and Facility Predictors of Disruptive Behaviors in Nursing Homes
 Source: Annual Meeting of the Gerontological Society of America
- Authors: Kemper, Peter, Spillman, Brenda and Murtaugh, Christopher
 Title: A Lifetime Perspective on Proposals for Financing Nursing Home Care
 Source: Annual Meeting of the American Public Health Association
- Authors: Kemper, Peter
 Title: Case Management Agency Systems of Administering Long Term Care: Evidence from the Channeling Demonstration
 Source: The Gerontologist December, 1990
- Authors: Kemper, Peter
 Title: Living Arrangement and the Demand for Home Care: An Illustrative Theoretical Model
 Source: Division of Long Term Care Studies Program Note
- Authors: Kemper, Peter and Murtaugh, Christopher
 Title: Long Term Care Financing Reform: Implications of New Evidence on Lifetime Nursing Home Use
 Source: Annual Meeting of the Association for Health Services Research
- Authors: Laforge, Robert and Spector, William
 Title: The Relationship of Vision and Hearing Impairment to One-Year Mortality and Functional Decline
 Source: Annual Meeting of the American Public Health Association
- Authors: Lemrow, Nancy, Adams, David, Coffey, Rosanna, and Farley, Dean
 Title: The 50 Most Frequent Diagnosis-Related Groups (DRGs), Diagnoses, and Procedures: Statistics by Hospital Size and Location
 Source: Hospital Cost and Utilization Project
- Authors: Leon, Joel and Lair, T.
 Title: Functional Status of the Noninstitutionalized Elderly: Estimates of ADL and IADL Difficulties
 Source: National Medical Expenditure Survey Research Findings, Number 4.
- Authors: Mathiowetz, Nancy and Moeller, John
 Title: Prescribed Medicines: A Summary of Use and Expenditures by Medicare Beneficiaries
 Source: National Medical Expenditure Survey Research Findings, Number 3.

- Authors: Monheit, Alan., and Schur, Claudia.
 Title: **Health Insurance Coverage of Retired Persons**
 Source: National Medical Expenditure Survey Research Findings, Number 3.
- Authors: Murtaugh, Christopher, Kemper, Peter and Spillman, Brenda
 Title: **The Risk of Nursing Home Use in Later Life**
 Source: Medical Care 28(10):952-962, 1990
- Authors: Murtaugh, Christopher and Kemper, Peter
 Title: **Risky Business: Long Term Care Insurance Underwriting**
 Source: Annual Meeting of the American Public Health Association
- Authors: Murtaugh, Christopher
 Title: **Discharge Planning in Nursing Homes**
 Source: Annual Meeting of the American Public Health Association
- Authors: Murtaugh, Christopher and Freiman, Marc
 Title: **The Hospitalization of Nursing Home Residents**
 Source: Annual Meeting of the American Public Health Association
- Authors: Spector, William and Jackson, Mary E.
 Title: **Characteristics Associated with Disruptive Behaviors in Nursing Homes**
 Source: Annual Meeting of the American Public Health Association
- Authors: Spector, William and Takada, H. A.
 Title: **Characteristics of Nursing Homes that Affect Resident Outcomes**
 Source: Journal of Aging and Health (forthcoming)
- Authors: Spector, William
 Title: **Cognitive Impairment and Disruptive Behaviors Among Elderly Persons Living In the Community: Implications for Targeting Long-Term Care**
 Source: The Gerontologist (forthcoming)
- Authors: Spector, William
 Title: **Functional Disability Scales**
 Source: In Spilker, B. (Ed.) Quality of Life Assessments in Clinical Trials. 1990. New York: Raven Press, pp. 115-129
- Authors: Spector, William
 Title: **Measuring Cognitive Impairment with Large Data Sets**
 Source: In Issues in the Measurement of Cognitive Impairment for Determining Eligibility for Long-Term Care Benefits. September, 1990. Washington, DC: American Association of Retired Persons, pp. 72-79

- Authors: Spector, William
 Title: Cognitive Impairment, Disruptive Behaviors, and ADLs:
 Evidence from the 1984 National Long Term Care Survey
 Source: Annual Meeting of the Gerontological Society of America
- Authors: Spector, William and Kemper, Peter
 Title: Hours of Care, the Interaction of Cognitive Impairment
 with ADLs: Evidence from Channeling
 Source: Annual Meeting of the Gerontological Society of America
- Authors: Spillman, Brenda and Kemper, Peter
 Title: Lifetime Spenddown to Medicaid Eligibility in Nursing
 Homes
 Source: Annual Meeting of the Gerontological Society of America
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 Title: Long Term Care Arrangements for Elderly Persons with
 Disabilities: Private and Public Roles
 Source: Annual Meeting of the American Public Health
 Association
- Authors: Stone, Robyn and Kemper, Peter
 Title: Spouses and Children of Disabled Elders: How Large a
 Constituency for Long Term Care Reform?
 Source: The Milbank Quarterly 67(3-4):485-506, 1989
- Authors: Stone, Robyn and Murtaugh, Christopher
 Title: The Elderly Population with Chronic Functional
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 Source: The Gerontologist 30(4):491-496, 1990
- Authors: Stone, Robyn and Short, Pamela Farley
 Title: The Competing Demands of Employment and Informal
 Caregiving to Disabled Elders
 Source: Medical Care 28(6):513-526, 1990

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

AGING

OBLIGATIONS

<u>FY 1988</u> <u>Actual</u>	<u>FY 1989</u> <u>Actual</u>	<u>FY 1990</u> <u>Actual</u>	<u>FY 1991</u> <u>Estimate</u>	<u>FY 1992</u> <u>Estimate</u>
\$5,898,826	\$7,635,000	\$18,696,800	\$38,562,000	\$38,900,000

HEALTH RESOURCES AND SERVICES ADMINISTRATION
Bureau of Health Professions

Aging

Four prototype regional Geriatric Education Centers (GECs) originated in 1983. In 1985, 16 additional centers were established, and in 1986 the number of centers reached a total of 22. In FY 1987, a total of \$9,306,742 was awarded for geriatric activities. Included in this amount was \$8,570,154 to support 31 GECs. These centers involved over 200 professional schools, teaching hospitals, teaching nursing homes, and other entities located in 25 states and Puerto Rico. In FY 1988, \$9,543,122 supported 33 GECs. In FY 1989, \$10,653,123 supported 38 GECs. In FY 1990, \$9,280,178 supported 33 GECs. These centers emphasize training of health professions faculty so that they will be more knowledgeable regarding the special health problems of geriatric patients in order to properly educate and train health professions students in this area. Multidisciplinary curriculum development, expert consultation, resource sharing, technical assistance, and training for health practitioners are also carried out within the geographic areas served by these centers. The ultimate goal is to improve the quality of health care delivered by health professionals so that the independence and mobility of the elderly may be increased. In September 1990, the leaders of the nationwide network of Geriatric Education Centers participated in a workshop in Tampa, Florida to explore a wide range of issues including meeting the needs of minority and rural elderly, and strengthening linkages among the Centers and with other organizations. A contract in the amount of \$90,728 was awarded in FY 1989 to the University of South Florida for this sixth GEC workshop.

In FY 1990, 23 Nursing Special Projects received awards totaling \$2,621,772. These projects included inservice educational programs for licensed practical nurses working with the aged, gerontological training programs for nurse educators, and educational programs for practicing nurses in the assessment and management of the frail elderly. Project activity was based in acute care settings and in the community as well as nursing homes.

Fifteen nurse practitioner programs received awards totaling \$1,782,906 to prepare registered nurses as geriatric/gerontological nurse practitioners. As nurses with advanced academic preparation and clinical training, they are prepared as primary health care providers to manage the health problems of the elderly in a variety of settings, such as long-term care facilities, ambulatory clinics and the home. They provide nursing care which includes the promotion and maintenance of health, prevention of disease, assessment of health needs, and

long term nursing management of chronic health problems. Emphasis is placed on teaching and counseling the elderly to actively participate in their own care and to maintain optimum health.

The Advanced Nursing Education Program awarded \$1,227,442 to nine programs to support curricula development to prepare clinical specialists in the care of the aged. Graduates of these programs are prepared broadly to meet a wide range of needs relative to the elderly in many settings, but are particularly prepared to deal with the older individual who is acutely ill. In addition, the program prepares nurses who can teach and do research in this important field.

The Area Health Education Center (AHEC) program awarded a total of \$536,073 among 15 of 22 AHECs which indicated emphasis in geriatric education. These educational and training activities benefitted an estimated population of 123,475 (including trainees). Four of the awards were for special initiatives to develop programs targeted to health care issues of the elderly, including the reduction of substance abuse and medication mismanagement, treatment compliance, and to provide enhanced training experiences for residents in rural areas.

Geriatrics training components will be developed by three grantees under the new Health Education and Training Centers program. A total of \$88,922 was awarded for this purpose, and it is estimated that the training will affect 170 health professionals.

All 38 Physician Assistant Training program grantees have instituted training activities in geriatrics. Funds in the amount of \$107,675 were awarded among 13 of the grantees specifically for their efforts in this area. An estimated 2,106 trainees would be affected.

Seventeen predoctoral grantees and 106 graduate program grantees under the Family Medicine Training program indicated they were actively involved in the development, implementation and evaluation of their geriatrics curriculum and training. Thirty of the residency program grantees received funds totaling \$1,981,083 specifically for developing and enhancing geriatrics curriculum and training. These efforts will benefit 55 predoctoral students and 1,022 residents. In addition, 25 faculty development programs reported that they provided geriatrics training benefitting an estimated 1,598 faculty. Six of the section 780 Family Medicine Departments program grantees received awards totaling \$450,887 for the purpose of strengthening geriatric training and carrying out research activities in this area.

The General Internal Medicine and General Pediatrics Residency Training programs reported 38 grantees who provided geriatric medicine training to approximately 268 residents. A total of \$130,251 was awarded to eight of the programs for their efforts. In addition to graduate training, four grantees under the faculty development program indicated that their geriatric emphasis would affect about 24 faculty, but no specific funds were received for these activities.

Nine grantees receiving support for Podiatric Primary Care Residency Training under section 788(e) authority have included curricular emphasis in geriatric health which will benefit an estimated 41 residents. These grantees received a total of \$39,666 for this purpose.

Under the program for Faculty Training Projects in Geriatric Medicine and Dentistry (section 789(b)), 23 grantees received a total of \$4,224,000 to provide geriatric faculty training experiences for 109 fellows.

AGING

Obligations

	<u>1988</u> <u>Actual</u>	<u>1989</u> <u>Actual</u>	<u>1990</u> <u>Actual</u>	<u>1991</u> <u>Estimate</u>	<u>1992</u> <u>Estimate</u>
<u>Public Health Service:</u>					
<u>Health Resources and</u>					
<u>Svcs. Administration:</u>					
Bureau of Health					
Professions					
H.P. Special Educ.					
Initiatives.....	\$12,439,317 <u>1/</u>	\$10,653,123 <u>2/</u>	\$9,280,178 <u>3/</u>	\$9,490,000 <u>4/</u>	---
Nursing Special					
Projects.....	2,019,980	2,412,811	2,621,772	2,085,400	---
Nurse					
Practitioners.....	1,366,940	1,460,069	1,782,906	1,800,000	---
Advanced Nurse					
Training.....	1,121,823	1,554,004	1,227,442	1,224,258	---
Area Hlth. Ed. Ctrs.	982,844	661,305	536,073	550,000	---
Health Education					
and Training Ctrs..	---	---	88,922	100,000	---
Physician					
Assistants.....	53,839	106,291	107,675	110,000	---
Family Medicine					
Residencies.....	1,998,669	1,481,819	1,981,083	2,190,000	---
Family Medicine					
Departments.....	---	403,025	450,887	450,000	---
General Internal					
Medicine and					
Pediatric					
Residencies.....	138,405	136,140	130,251	---	---
Podiatric Primary					
Care Residency.....	---	145,650	39,666	50,000	---
Geriatric Faculty					
Fellowships					
Sec. 788(b).....	---	<u>3,100,000</u>	<u>4,224,000</u>	<u>4,120,000</u>	---
Total.....	\$20,121,817	\$22,114,237	\$22,470,955	\$22,171,658	---

1/ FY 1988 Grants: S.788(d), 788(b) and 301/788 = \$9,543,122; S.788(e) = \$2,800,000.

Contracts: S.788(d), 788(b) and 301/788 = \$96,195.

2/ FY 1989 Grants: S.788(b), 789(a) & 301 = \$10,653,123.

3/ FY 1990 Grants: \$9,171,500; FY 90 Contracts: \$108,678.

4/ FY 1991 Grants and Contracts: \$9,490,000 (est.).

Alcohol, Drug Abuse, and Mental Health Administration

Aging Research

National Institute of Mental Health

Between 1900 and 1988 the percentage of the elderly in the U.S. population rose from 4 percent to 12 percent. In just 5 years, from 1980 to 1985, the number of centenarians increased from 15,000 to 25,000. Unfortunately, a longer life span does not necessarily assure active and independent years. Improving the quality of later life is among the most pressing of the Nation's health problems.

Mental disorders in the elderly are quite common and wide ranging; some particular disorders have a disproportionate impact. Approximately 15 percent of Americans over 65 suffer from significant mental health problems. Difficulties abound in discriminating some disorders from others, e.g. depression from dementia, and whether an individual should be diagnosed with any mental disorder; yet the ability to make accurate diagnoses is crucial to the management and treatment of mental disorders and this is especially true in the elderly. Alzheimer's disease, depression, anxiety, sleep disorders, cognitive impairments and schizophrenia are among the areas currently undergoing study in NIMH research projects focussed on the elderly.

Dementia/Alzheimer's Disease

Dementias, including Alzheimer's disease, represent a devastating problem in this population. Of the more than 70 identified types of dementia, Alzheimer's disease is the most common, accounting for approximately 60 percent of all dementia. Best estimates indicate that at least 4 million Americans presently suffer from Alzheimer's disease or related dementias. Alzheimer's disease victims have a specific set of symptoms, but a definitive diagnosis is now possible only by examination of brain tissue after death. Depression sometimes mimics the symptoms of early Alzheimer's disease, and this similarity of symptoms complicates diagnosis and treatment. The changes in the brain that are the hallmarks of the disease are most likely caused by genetic, environmental, immunologic and/or metabolic factors. Some researchers in genetic linkage analysis have proposed a multi-gene causal model of Alzheimer's disease.

Depression Can Shorten Life

Depression is a relatively frequent and often unrecognized problem among the elderly. In a recent study by Dr. Dan Blazer at Duke University 43 percent of patients had their first spell of depression after age 59. Depression is not just debilitating, it also shortens life. Recently Dr. Carl Eisendorfer at the University of Miami determined that depression is part of a process that increases the possibility for death and sickness especially among the elderly. This has important implications because some older people may slip into an almost permanent, low-level depression. Many factors that can produce depression converge in old age:

deaths of spouse and friends, social isolation, Alzheimer's disease and other mental disorders, and loss of the self-esteem that comes from being employed. Clinical depression is likely to last longer in the elderly with less chance for spontaneous remission. But the most tragic fact is that 85 percent of the depressed elderly don't seek help, and many do not even know they are depressed.

Suicide In The Elderly

While having any mental disorder is a risk factor for suicide, depression is a contributing factor in many suicides in this age group. The suicide rate for all ages and races was 12.7 per 100,000 population in 1987, but the rate was 19.4 for men and women ages 65 to 74, 25.8 for men and women ages 75 to 84, and 22.1 for persons aged 85 and over. White males over age 85 have the highest suicide rate of any group (55.8 per 100,000). If the suicide rate does not change, the number of suicides in those over age 65 will double, simply as a result of the increase in number of elderly Americans.

Accomplishments

Imaging Studies

Imaging technology is being used to explore for diagnostic markers of a number of late-life mental illnesses, as well as for tracking brain changes that may result from treatment. Researchers are comparing Magnetic Resonance Imaging (MRI) scans of the brain in persons who are aging normally with those of elderly persons referred for electroconvulsive therapy (ECT) for depression. More numerous and severe brain abnormalities are apparent on the MRI scans of these depressed elderly patients. Those whose depression begins late in life have more atrophy in the brain's cortex. Preliminary analyses indicate that depressed patients with more brain abnormalities are less responsive to electroconvulsive therapy and maintain more symptoms of depression. Identifying brain characteristics that predict ECT effectiveness will be an important step for treatment and understanding the course of late life depression.

Using high-resolution MRI, Dr. David Amaral at the Salk Institute is studying amnesic patients to identify abnormalities in the brain's hippocampus. Age-related neurological changes occur earlier in the hippocampus than in many other brain structures. The hippocampus is especially vulnerable to damage from a variety of sources including stroke, toxic chemicals and alcohol. It is a central structure in the ability to remember day to day events and the ability to use spatial cues. This research has revealed hippocampal abnormalities in patients with severe and selective memory impairment.

Dr. Patricia Prinz at the University of Washington is using electroencephalographic (EEG) activity to discriminate mild dementia from normal aging and from elderly depression. She has been able to correctly differentiate 85 percent of normal elderly persons from mildly demented subjects. Because the accuracy of a specific diagnosis in the earliest stages of dementia has been so poor, these finding represents a significant development.

A Potential Diagnostic Protein Found In Alzheimer's Disease Patients
 At Albert Einstein College of Medicine, Dr. Peter Davies has discovered an abnormal protein, called A-68, in the brains of patients with Alzheimer's disease. This discovery may ultimately lead to a clinically useful diagnostic test for this disorder. Dr. Davies developed a monoclonal antibody that identifies the abnormal Alzheimer's disease associated protein in 85 percent of patients. Research is continuing to determine whether the protein can be reliably assessed in blood or cerebrospinal fluid.

Alzheimer's Disease Affects Specific Cognitive Function
 The effects of Alzheimer's disease on speech and memory has led Dr. Kathryn Bayles at the University of Arizona to develop a series of sensitive communication disorder tests. These tests demonstrate that even mildly affected Alzheimer's disease patients perform significantly less well than controls. Dr. Bayles has also devised a series of evaluations for late-stage Alzheimer's disease patients. Previously, the severe cognitive impairment of such individuals led them to be considered untestable. Dr. Bayles has found considerable variation in communication function. Mechanics of word reading and writing from dictation are easier and less affected than remembering the names of people and things.

Current Activities

Diagnostic Efforts In Alzheimer's Disease And Depression
 Scientists in the Intramural Program are focusing on the frequent overlap of symptoms in depressed and demented patients. A diversity of methods is being used to test both Alzheimer's disease and depressed patients. Some of these measures are capable of distinguishing demented from depressed patients. However, some of these measures show remarkable similarities among diagnostic groups, suggesting biological as well as clinical overlap. Another intramural group headed by Dr. Trey Sunderland has developed, and is continuing to test, a Dementia Mood Assessment Scale, designed specifically to rate mood in language-forgetful, and sometimes entirely nonverbal, Alzheimer's disease patients. This scale is helpful in tracking variable mood states over the course of illness, and it may provide clues as to when antidepressant treatment is indicated.

Genetic Studies in Alzheimer's disease
 Genetic inheritance is the only etiologic factor identified for Alzheimer's disease, and thus the only confirmed clue to the mystery of the disease. In earlier NIMH-supported research, Dr. Leonard Heston at the University of Minnesota discovered a remarkable clue to familial Alzheimer's disease in the form of an association with Down's syndrome. Initially it was hoped that the genes for the two diseases might be closely linked, however the most recent studies have shown that the genes must reside at separate points on chromosome 21. Another linkage analysis study is now investigating a finding of increased membrane fluidity in blood platelets in Alzheimer's disease patients. This blood abnormality is

hypothesized to be a product of the Alzheimer's disease gene and may lead to a diagnostic technique.

As part of a larger initiative on the genetics of mental illness, NIMH funded three sites (Harvard University, Johns Hopkins University, and the University of Alabama at Birmingham) to focus efforts on genetic research in Alzheimer's disease. The primary goal of the initiative is to establish a national resource of cell lines and clinical data from reliably diagnosed index cases and key relatives. These tissue samples will be a permanent source of DNA, allowing characterization of the DNA sequences critical in Alzheimer's disease. NIMH has also been working with the National Institute on Aging to coordinate the efforts of their respective Alzheimer's disease gene bank initiatives, and will continue to encourage collaboration between investigators to ensure comparability of results.

Neurotransmitter Studies May Lead To Medications for Alzheimer's Disease

Several grantees are studying chemical neurotransmission abnormalities in the brains of Alzheimer's disease patients. Since loss of neurons that communicate via acetylcholine and acetylcholine depletion are almost always observed in the brains of those who have died from Alzheimer's disease, studies of this neurotransmitter have direct implications for understanding the disease. Dr. Paul Newhouse at the University of Vermont is employing a series of pharmacological probes to investigate how loss of brain cells and receptors correlates with cognitive deficits. By exploring the effects of a nicotine antagonist, mecamylamine, Dr. Newhouse hopes to determine whether the cognitive and behavioral disruptions of Alzheimer's disease can be prevented.

A naturally occurring chemical, cholinesterase, is suspected to cause depletion of acetylcholine. Investigators at Southern Illinois University are now conducting a clinical trial of metrifonate, a chemical found to inhibit the production of cholinesterase by as much as 80 percent in a previous study with Alzheimer's patients. Cognitive performance in those patients was improved according to various assessments, including reports by family members.

Two-Drug Combination Therapy

NIMH intramural scientists are developing new strategies to delay progression of symptoms of Alzheimer's disease. Previous work showed that the monoamine oxidase inhibitor, L-deprenyl, which delays symptoms of Parkinson's disease, was helpful in the symptomatic treatment of Alzheimer's disease. Long term investigations are underway to evaluate the possible neuro-protective effects of L-deprenyl. In an effort to expand the horizon of dementia therapies, the approach of combining different pharmacologic agents (e.g. physostigmine with L-deprenyl) is now being used. Such combination approaches may prove to be the dominant therapeutic strategy for Alzheimer's disease in the 1990s.

Depression in Alzheimer's Disease Patients and Caregivers

Dr. Linda Teri at the University of Washington has implemented a behavioral treatment that trains family members in skills designed to decrease depression in the Alzheimer's disease patient. Although research concentrated on depressed patients, depression was also observed in over half of the caregivers, suggesting that contending with both Alzheimer's disease and depression in the patient may put caregivers at risk for depression themselves. NIMH has placed particular emphasis on family studies, and for several years has had in force an announcement soliciting grant applications for "Research on Family Stress and the Care of Alzheimer's Disease Victims." NIMH is funding several projects focusing on the chronic impact of caregiving and the relationships between psychological distress and physical health. Previous results from Drs. Janice Kiecolt-Glaser and Ronald Glaser at Ohio State University indicated that family caregivers of Alzheimer's disease patients not only have increased rates of infectious illness and symptoms of clinical depression, but often suffer suppression of their immune systems. Ongoing studies are exploring how caregivers in different contexts---those caring for the patient at home, those caring for a patient in an institution, those who are recently bereaved---vary in immune function.

At the Palo Alto Veterans Medical Center, Dr. Dolores Gallagher is studying caregivers and has found the rate of reported anger was 67 percent, with depressed mood identified in 54 percent of caregivers. Dr. Gallagher has developed two interventions, one aimed at anger management and the other at depression. Pilot data show that the anger management intervention may be particularly effective for caregivers.

An incidental finding from a study of neurotransmitter concentrations in the cerebrospinal fluid of Alzheimer's disease patients demonstrated dramatic elevations of gamma-aminobutyric acid (GABA) in a segment of the control group--chronically stressed, yet well functioning, caregiver spouses. Dr. Nunzio Pomara at the Nathan Kline Institute and New York University found no concomitant increase in markers for other neurotransmitters such as dopamine, serotonin or norepinephrine. The meaning of these findings is unclear, and further research is required to replicate the results and to determine the implications of the GABA elevations.

Dr. Leonard Pearlin at the University of California at San Francisco, is attempting to identify the range of stressors experienced by caregivers in conjunction with their access to and use of formal and informal supports. In another study, caregiving "careers" are being followed, in which new caregivers will be studied until the death of the care recipients. Dr. Powell Lawton, Dr. Rachel Pruchno, and Ms. Elaine Brody at the Philadelphia Geriatric Center, will study these careers for the impact of family dynamics, length of caregiving, and personal characteristics of the caregivers.

Sleep Disorders Are Not A Normal Part Of Aging

Although sleep patterns change with age and sleep problems appear widespread among the elderly, they are not a normal part of aging and should not automatically be treated with drugs. Disorders of sleep afflict over half of people 65 and older who live at home and about two-thirds of those who live in long term care facilities. A recent consensus conference cosponsored by NIMH found that the ability to sleep decreases with age more than the need to sleep; but in healthy older people without accompanying medical disease, there are very few complaints of sleep disorders. An improved understanding of sleep disorders in the elderly will facilitate better treatment strategies, including non-pharmacological methods.

Research continues to clarify the relation between persistent sleep abnormalities and mental disorders. Several longitudinal studies are examining sleep characteristics as risk factors for future depression. One study is following patients with major depression who are currently in maintenance therapy; a second is following patients who are grieving over the death of their spouses; and a third is studying healthy elderly. Analyses of these groups may highlight the interrelationships among rapid eye movement (REM) sleep abnormalities, the severity of psychopathology, and disruption in normal social rhythms of life. Recent studies have reported that a reduced amount of REM time (before treatment) is strongly associated with recurrence of depression and that one night of total sleep deprivation correctly differentiated patients with depressive pseudo-dementia from patients with Alzheimer's disease or other dementias.

Sundowning

Severe problems in sleeping often lead to institutionalization of the elderly for safety reasons. Elderly demented patients who wander in the night are a hazard to themselves and their caretakers. Another problem for some elderly demented patients is "Sundowning," a term that describes the onset or exacerbation of delirium during the evening or night, with the improvement or disappearance of delirium during the day. Sundowning is a major problem in the middle and late stages of disorders, such as Alzheimer's disease.

The relationship of disturbed sleep, altered sleep-wake cycles, breathing/snoring problems, daytime sleepiness and Sundowning to the disabilities associated with dementia is being studied. Preliminary data on sleep changes in dementia patients indicate that patients with normal oxygen levels during sleep either showed less confusion in the morning, or were otherwise unchanged from the previous night. Researchers are examining the possibility that increased confusion from lack of oxygen during sleep may contribute to Sundowning. Studies of the clinical efficacy of several commonly used medications for Sundowning are also being undertaken.

Non-Pharmacological Treatments For Sleep Problems

Poor sleep may account for the disproportionate prescription of sedative hypnotics for the elderly. The elderly comprise 12 percent of the population but account for about 30 percent of the sleeping

pills consumed. Sedative use may lead to exacerbation of disrupted breathing and daytime carryover effects such as sedation, falls, cognitive impairment, and amnesia. Thus, alternatives to pharmacotherapy approaches to sleep problems are needed. NIMH researchers are assessing the relative effectiveness of cognitive behavior therapy, new types and new levels of medication, and the combination of the two therapies for sleep difficulties. Another study is evaluating the effects of increased aerobic fitness on sleep quality.

Sleep Restriction Therapy (SRT) is also being tested as a treatment for sleep problems. The elderly often report more naps than younger adults. However, the daytime sleepiness that may accompany napping may lead to decreases in cognitive functioning. SRT improves sleep quality by restricting excessive time in bed and creating a modest level of sleep deprivation resulting in more consolidated sleep. This treatment's effect on depressive symptoms will also be tested.

Aging And Memory Function

Understanding basic mechanisms of memory function is critical for understanding the mechanics of Alzheimer's disease. Research by Dr. Carl Cotman at the University of California at Irvine, suggests that it is possible to re-grow neuronal connections that have been severed in the hippocampus. The hippocampus is severely affected in Alzheimer's disease. Work is continuing on this promising finding which may make it possible to restore memory function.

Dr. Carol Ann Barnes at the University of Colorado is seeking a detailed understanding of age-related changes in the hippocampus. She has found that the major defect in older rats may lie in the more rapid decay of neural activation called long-term potentiation (LTP). If the hypothesis that LTP underlies spatial learning and memory is correct, the faster decay of this process could result in faster forgetting of spatial relationships. More evidence that this may be true has been provided by a study showing that the drug, pentoxifylline, both extends the decay time of LTP and improves spatial performance in old animals.

Using multiple brain imaging techniques, Drs. Alan Kluger and Mony DeLeon of New York University are investigating the connections among cognitive impairment, motor dysfunction and white matter brain lesions. Previous research found a decreased density of white matter in the brains of Alzheimer's disease patients. The Alzheimer's disease patients also had consistent and significant decreases in brain metabolism. Their current longitudinal research is testing the hypothesis that both Alzheimer's disease patients and normal elderly persons with white matter changes are at greater risk for cognitive/motor deterioration over time. Although these changes may be independent of Alzheimer's disease, they may add significantly to the brain-damage burden of the patient.

Cognitive Disorders In Elderly Diabetics

Cognitive disorder refers to disruptions in the mental process of comprehension, judgement, memory and reasoning. Besides diagnosable

mental disorder, physical illness can precipitate cognitive disorder. Evidence is gradually accumulating that poor control of glucose in elderly diabetics may also have untoward effects on cognitive function. The prevalence of non-insulin dependent diabetes mellitus, type 2, goes up with age, but the therapeutic approaches are not well-defined. The fear of severe side-effects, such as hypoglycemia and decreased life expectancy often lead to an extremely conservative treatment approach at the expense of good glycemic control.

Researchers at Stanford University School of Medicine are evaluating the effect of glycemic control treatment on cognitive and emotional functioning in elderly patients with type 2 diabetes. Since several studies have suggested that improvement in both neuropathy and retinopathy can occur when good metabolic control is established, the investigators hypothesize that similar positive changes in behavioral functioning due to treatment might also be expected. Findings from this study may offer the promise of improved mental health for elderly diabetic patients.

Culturally and Educationally Appropriate Assessment Instruments

Another challenge to accurate assessment of cognitive function is the literacy level presumed by the testing instruments. Dr. Ramon Valle of San Diego State University has translated into Spanish and is validating for use with older Hispanics, two commonly used cognitive screening instruments. Dr. Valle has found that the Hispanic versions of these screening measures are valid with literate Hispanics but inadequate for the assessment of dementia in poorly educated individuals. This project addresses the need for culturally and educationally fair cognitive assessment devices for one segment of the growing ethnic minority elderly population.

Medication Side Effects Can Be Particularly Pronounced In Older Patients

There is a profound need for safe and effective medications for mental disorders that afflict the elderly. Aging can interfere with drug metabolism and drugs for depression can interact with other medications the individual is taking. The relationship between a prescribed drug and behavior abnormalities, memory loss or intellectual deterioration often goes undetected, and the problem may be diagnosed as mental illness or senility. More medications may be prescribed, often making matters worse. These factors make medication testing, evaluation and development for the aging mentally ill an urgent subject for research.

Behavioral disturbances are frequently another complication of Alzheimer's disease. When Alzheimer's disease patients manifest psychosis or agitation they are most often treated with neuroleptic medications--the same antipsychotic treatments used with patients who suffer from hallucinations and delusions. Tardive dyskinesia is a side effect of long term use of such medications. Its symptoms are involuntary, jerky muscle movements. Tardive dyskinesia can be a significant problem in severely mentally ill elderly patients for several reasons: the risk of developing tardive dyskinesia

increases considerably with age; the length of neuroleptic exposure necessary to produce the disorder tends to be much shorter in older adults; and the symptoms are more likely to be severe and persistent. NIMH-supported research is underway among elderly psychiatric patients who have had very little lifetime neuroleptic exposure to determine the incidence of and risk factors for tardive dyskinesia in older patients. Dr. Davangere Devanand at Columbia University is addressing the lack of adequate data on the effects and safety of neuroleptic medications used to treat behavioral disturbances in Alzheimer's disease patients. His study is assessing the efficacy and side effects of a traditional dose of oral haloperidol versus a low dose on symptoms, activities of daily living, and cognitive functioning. These studies are expected to contribute to the knowledge base for safer therapeutic medication for elderly patients.

Schizophrenia In The Elderly

Although schizophrenia usually first appears in young adulthood, late-onset schizophrenia has recently been recognized. This is primarily a disorder of women and is frequently associated with hearing loss. Common features of late-onset schizophrenia (LOS) in the elderly have recently been identified and include bizarre delusions (typically persecutory), auditory hallucinations, persistent illness and response to relatively low doses of medication. Thought disorder, inappropriate affect, and sensory deficits are not common in LOS. History, examination, and laboratory tests have revealed no evidence of any diagnosable neurological disorder. Research is currently examining the structural and dopamine D₂ receptor changes in the brain associated with LOS. It is hoped that these results along with clinical ratings that document the occurrence of symptoms will elucidate the differences between the two types of schizophrenia.

Further examination of the neuropsychological, brain-imaging, and treatment response-characteristics of LOS, is expected to distinguish particular LOS subtypes. One subset of patients is predicted to have significant neuropsychological deficits, structural abnormalities shown by imaging, and poor therapeutic response to neuroleptics in addition to a greater risk of tardive dyskinesia. Another, smaller group is expected to have a diagnosable dementing disorder that initially presents with schizophrenia-like clinical symptoms. Researchers expect to use these diagnostic subtleties to help develop targeted behavioral and biological treatment approaches. The goal of specific treatment medications geared to dopamine D₂ receptors is also being pursued.

Another important research effort is the attempt to discern whether the dementia that appears in elderly schizophrenia patients is similar to that found in Alzheimer's disease or multi-infarct dementia. The effects of Alzheimer's disease on brain cells are well known, but a similar mechanism in schizophrenia remains to be documented. Elderly schizophrenic patients are being tested for levels of functioning and cognition. After death, the structure and composition of their brain tissue will be studied. Insight into the

etiology and neuropathology of a schizophrenic "dementia" has practical and theoretical importance. If dementia in schizophrenia is like Alzheimer's disease, similar pharmacological approaches could be tried in both populations. On the other hand, a "dementia" unique to schizophrenia would promote investigations of the etiology of the cognitive decline in this illness, and could be an important clue to the underlying pathogenesis of schizophrenia.

Services Research

The elderly persistently mentally ill are the subject of another facet of NIMH research that is studying the relations among the social, environmental and health factors that influence utilization and success of family care and mental health services.

One investigator is following four age cohorts of middle-aged and elderly individuals with diagnoses of major mental disorder for five years. This study will attempt to determine how health and mental health services, social supports, family stressors and other factors affect adjustment in these persistently mentally ill elderly. By identifying factors contributing to better outcome, interventions to improve functional independence may be made.

Elderly parents who care for adult children with a severe mental illness frequently experience significant hardships and may become depressed. Researchers are evaluating this population of elderly parents to assess their objective and subjective burdens, including the factors which contribute to the perception and reality of that burden. One factor being examined is the extent to which formal services to the mentally ill adult child and the family serve as a buffer for the older parents.

A currently funded service demonstration project is evaluating the effectiveness of providing the services of trained respite care workers to caregiving families of Alzheimer's disease patients, in terms of both improvements in the families' quality of life and reductions in the patients' institutionalization rates. Another project is evaluating a model program for elderly persons disabled with Alzheimer's disease or other chronic mental disease, that encompasses individual assessment and treatment planning, case management, and supported referral. Patients in the program are being compared with controls in terms of functioning, maintenance of residence in community settings, services utilization, mortality and morbidity rates, and quality of life.

The larger number of elderly Americans has had implications for the institutions that provide care for those most disabled by physical or mental disorders. Presently, 5 percent of the Nation's aged live in institutions. Of these, about 12 percent are in mental hospitals, with the remainder in nursing and other types of homes for the aged and chronically ill. Geriatric patients comprise 16 percent of beds in public psychiatric hospitals, and an estimated 80 percent of those age 65 and older in nursing homes have some degree of mental impairment. Since there are approximately 1.5 million Americans living in nursing homes, identification and

treatment for depression is a positive step toward improving quality of life.

Efforts toward improving institutional living face several difficulties. Despite goals of minimal restrictions and personal freedom, institutions caring for the elderly face a need for programs to deal with wandering and confused patients and the possible difficulties arising from the use of behavior modifying drugs. Another problem is the resistance by both family and patients to taking advantage of existing mental health resources due to the stigma attached to mental disorder. Projects currently underway include such topics as work stress and morale of nursing home employees, and the effect of staff expectations on residents' functional status. The care of the elderly residing in personal care homes, a type of facility where many mentally ill elderly are found, is being examined at the Community Services Institute in Narberth, Pennsylvania. Personal care homes have not traditionally provided mental health care, and Dr. Leonard Gottesman is studying strategies for improving care of mentally ill residents of such homes, as well as their cost effectiveness, since these facilities are replacing large state hospitals as homes for the mentally ill.

Training Of Research And Clinical Personnel

NIMH has developed a Research Teacher/Investigator award program with 10 awards presently being supported for seven psychiatrists and three nurses. In addition, two young investigators are supported by Research Scientist Development Awards in their study of the etiology, pathogenesis and diagnosis of Alzheimer's disease. NIMH also supports a three-part clinical training program in Mental Health and Aging which focuses a portion of the curricula on Alzheimer's disease. Sixteen awards to various mental health disciplines are presently being funded: 4 individual faculty scholar awards, 4 institutional clinical training grants for minority students, and 8 institutional clinical training grants for general training.

Educational Materials And Information Dissemination

NIMH has an active information dissemination program on Alzheimer's disease. Efforts include distribution of the Fact Sheet on Alzheimer's Disease written especially for families, and dissemination of research findings to the field. The Fact Sheet has recently been updated, and the new version is now available.

In March 1990, NIMH held a workshop on the "Mental Health of Family Caregivers in Alzheimer's Disease and Related Dementias," in which leading researchers discussed current findings and future research needs regarding the interaction between physical and mental health in Alzheimer's disease caregivers, intervention strategies with families of Alzheimer's disease patients, and mental health services that take cognizance of family issues in Alzheimer's disease. A forthcoming volume based on this workshop will further define and foster new directions in services research on Alzheimer's disease.

Papers from a 1989 NIMH conference on "Age and the Organic Syndrome of Delirium" are also being prepared for publication. At this conference, investigators and clinicians discussed advances in assessing and understanding states of delirium in the elderly, identified current research needs, and considered changes in diagnostic nomenclature that may assist in improving medical diagnosis and treatment of states of delirium. Syndromes of delirium are frequently superimposed on demented patients' basic cognitive deficits, and often reflect underlying conditions that tend to be life-threatening, such as concurrent medical disorders or pharmacological toxicity.

Council And Advisory Panel On Alzheimer's Disease

NIMH currently provides the Deputy Executive Secretary and staff support for the Department of Health and Human Services' Council on Alzheimer's Disease and the Advisory Panel on Alzheimer's Disease. The Advisory Panel in 1989 published its first of four Congressionally mandated reports, in which it set forth recommendations for legislative and administrative actions to improve services for patients with Alzheimer's disease and related dementias and their families. It also set forth recommendations on how to provide for promising biomedical research on this disease. The Panel's second report updates topics covered in the earlier report, such as biomedical and services-oriented Alzheimer's disease research, financing of care, and eligibility for services, and addresses the special topics of personnel and training issues in the care of Alzheimer's disease victims.

The Future

By the year 2000, the percentage of elderly in the population is projected to be 13 percent. In the year 2030, 22 percent of the population will be elderly, with more than 64 million persons over 65 and more than 30 million over 75. There is a critical need for research in basic science to understand the chemical and molecular bases of mental disorder in the elderly. Another essential NIMH responsibility is to recruit and train new investigators in geriatric mental health and disorders and to support research career development.

New and useful medications with fewer side effects are needed to treat the elderly suffering from mental disorders. Drug interactions are also a problem in this age group. A recently established program, the NIMH medication development program, will expand the chemical synthesis and molecular modeling programs, establish a natural products collection program for isolation, purification and identification of potential new drugs. Another facet of the program will expand the neuroreceptor screening program. A concerted effort will be launched to establish models of treatment for the nursing home setting. The lack of valid treatment protocols for the elderly who experience multiple medical and psychiatric diagnoses necessitates the development of comprehensive, combination treatment plans.

Future directions of Alzheimer's disease research at NIMH include: 1) the molecular genetics of Alzheimer's disease; 2) biochemical analyses of the neuropathological characteristics that define Alzheimer's disease; 3) the role of nerve growth factors in Alzheimer's disease and the potential use of neural implants as a research tool; 4) identification of diagnostic markers for Alzheimer's disease--particularly markers useful at early stages of the disease; 5) further investigation with brain imaging techniques, such as PET and MRI, to study changes in brain structure and metabolism in Alzheimer's patients; 6) refinement of diagnostic procedures for Alzheimer's disease; 7) improved understanding of the pathogenesis and course of psychiatric and behavioral symptoms in Alzheimer's disease; and 8) evaluation of strategies for clinical intervention in Alzheimer's disease, including behavioral and psychopharmacological techniques for managing symptoms or arresting cognitive decline, and interventions and services for supporting family members and alleviating caregivers' stress.

National Institute on Alcohol Abuse and Alcoholism

Until recently the issues surrounding alcohol use among the elderly have received little attention; few studies have explored the effects of early patterns of alcohol use on later life outcomes and drinking patterns. One investigator has sought to clarify the well documented but poorly understood observation that the prevalence of heavy consumption appears to decrease with increasing age in the general population. This research found that early mortality among the heaviest drinkers contributed to decreasing consumption among older individuals. Other researchers have further demonstrated that lighter consumption by the current elderly is in part a cohort phenomenon--that is these individuals have had life-long patterns of lower consumption.

Alcoholism among elderly persons is often minimized because of the low reported frequencies of alcohol dependence among elderly age groups in community and population studies. Yet alcohol-related morbidity as reflected by hospitalization is substantially under-reported in the elderly. Since this is the fastest growing segment of the U.S. population, these areas will continue to merit further research. In one study, all patients over 60 years of age, taken as a group, demonstrated an alcoholism prevalence of 17 percent in the general hospital setting. While this prevalence is in the range of one-half that seen for younger hospitalized patients, it is approximately 3 to 4 times higher than that reported in the literature for elderly persons in the population at large. Elderly persons who suffer from alcoholism appear to represent a clinically select sample requiring health care services with a significantly higher frequency than elderly persons found in general population studies.

Although the prevalence of alcoholism among the elderly is less frequent, research suggests that alcoholic elderly probably use the hospital more frequently as judged by the number of admissions and by the percentage of total hospital days used by alcoholics in various age groups. It appears that elderly alcoholics go to the hospital significantly more often than their younger counterparts and stay for a significantly longer time. Based on this estimate from calculated data and prevalence figures, researchers conclude that elderly alcoholics probably account for a significantly larger share of the health care delivery resources than previously appreciated. Roughly speaking, while their prevalence was half that for younger groups, their per capita resource utilization was twice as high, resulting in nearly equal health care resource usage.

Multidisciplinary Aging Research Center. The National Alcohol Research Center at the University of Michigan will continue to develop strategies for early diagnosis and treatment of alcoholism in older individuals and work to determine how alcohol interacts with the normal aging processes to produce central nervous system abnormalities. The research approach is multidisciplinary and takes advantage of state-of-the-art noninvasive technologies to investigate alcohol-related abnormalities of the central nervous

system. The Center's combined investigation of aging and alcoholism is a valuable approach to a medical and social problem which has become increasingly serious.

Another area of particular interest is chronic myopathy, characterized by wasting of skeletal muscle, which may be present in as many as 25 to 60 percent of patients in clinical alcoholism facilities. Alcoholics tend to have impaired muscular coordination, which may be at least partly due to alcohol's effects on areas of the brain involved in motor activities. Researchers have been studying both muscular and psychomotor deficits to ascertain their relative contributions to motor dysfunction in alcoholics, and to describe patterns of alcohol intake most likely to produce ill effects. This study is expected to provide valuable information on patterns of alcohol abuse most likely to impair muscle functioning. Since older alcoholics are more susceptible to myopathy, this research will be of particular importance to this vulnerable population and will be useful in formulating recommendations to enhance this aspect of overall rehabilitation.

Alcohol abuse is a common factor in highway death and injuries and in fatal general aviation accidents. Over half of highway deaths are alcohol-related. Similarly, the National Transportation Safety Board found an average of 10.5 percent of fatal general aircraft crashes, 6.4 percent of fatal commuter airline crashes, and 7.4 percent of fatal airtaxi crashes involved pilots with positive blood alcohol tests. Because of these alarming statistics, recent research efforts have been directed at understanding how such factors as age, experience, and alcohol use interact with events in the actual driving or flying environment. Researchers investigating the interaction of age and alcohol on flight performance, found that communication tasks (accuracy in changing course and radio frequencies) were sensitive to both age and alcohol, while routine flying abilities (take-off, approach and landing) were impaired by alcohol, but not age. These results will contribute to improved aviation safety, and influence decisions that involve the regulation of pilots and the safety of passengers., ,

Prevention. Current activities and future plans include focussing on social factors in medication and alcohol use by the aged and the prevention of alcohol abuse among the nation's elderly. Research approaches may center on the implementation and testing of a full-scale intervention to reduce or prevent alcohol abuse in the later years of life; the conduct of research on institutions and processes to ascertain their potential utility as instruments of intervention; or the development of measurement tools to identify older people who are vulnerable to, or in the early stages of, problem drinking.

NATIONAL INSTITUTES OF HEALTH
National Institute on Aging

SPECIAL REPORT ON AGING

Introduction

From the basic biology of cell growth to studies of exercise physiology in older people, the National Institute on Aging (NIA) seeks new understanding of the complex and various ways that people age -- physically, emotionally, and psychologically. The Institute's portfolio includes studies of specific disorders that affect older people disproportionately. NIA-funded research is improving our understanding, diagnosis, and treatment of Alzheimer's disease (described in a separate report). In addition, NIA recently funded clinical trials that will identify interventions to reduce frailty and the incidence of falls in older people. The Institute's Claude D. Pepper Geriatric Research and Training Centers provide support and career opportunities for those interested in practicing geriatric medicine or conducting clinical aging research.

Other NIH institutes with an interest in aging research are the National Cancer Institute (NCI); the National Heart, Lung, and Blood Institute (NHLBI); the National Institute of Dental Research (NIDR); the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); the National Institute of Neurological Disorders and Stroke (NINDS); the National Institute of Allergy and Infectious Diseases (NIAID); the National Eye Institute (NEI); the National Institute of Environmental Health Sciences (NIEHS); the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); the National Institute on Deafness and Other Communication Disorders (NIDCD); the National Center for Research Resources (NCRR); the National Center for Nursing Research (NCNR); and the Office of the Director (OD).

Exercise Tests Predict Heart Disease

Early intervention is an effective strategy for improving the outcome of health care and containing its costs. Screening tests can frequently provide doctors with information needed to diagnose medical problems while patients are still relatively free of symptoms (asymptomatic). Because coronary artery disease is the leading cause of death in the United States, researchers are investigating ways to predict who is likely to have heart problems.

Intramural scientist Dr. Jerome Fleg and colleagues at NIA's Gerontology Research Center (GRC) in Baltimore, Maryland, used thallium scanning, a relatively new and noninvasive technique, in conjunction with the conventional treadmill exercise test to look for evidence of reduced blood supply to the heart (silent myocardial ischemia or SMI) in asymptomatic volunteers. SMI is

usually the result of coronary artery blockage. The 407 participants, age 40 to 96 years old, were drawn from the Baltimore Longitudinal Study of Aging (BLSA). Only those without clinical evidence of heart disease were included in the study.

Each participant took a maximal treadmill exercise test with standard electrocardiogram (ECG) monitoring. Doctors injected a trace amount of the radioisotope thallium into the person's arm at the peak of his or her effort. Multiple pictures of the heart taken at the conclusion of the treadmill test to detect the injected thallium tracer showed areas with inadequate blood supply as holes or filling defects in the pictures.

Dr. Fleg found that the prevalence of exercise-induced SMI increased from 2 percent in the fifth and sixth decades to 15 percent in the ninth decade. During the follow-up period (at intervals of 4 to 6 years) coronary events developed in 7 percent of the volunteers who originally had negative ECG and thallium scans, in 8 percent of those who had a positive result in either test, and in a striking 48 percent of those for whom both tests were positive. This result was independent of conventional risk factors such as age, hypertension, and fitness level.

Judicious use of the thallium scan, in conjunction with the treadmill test, may help in the early recognition of SMI in the at-risk population.

Physically Fit Women and Men Live Longer

Moderate levels of physical fitness--which can be attained by most older adults--are associated with lower risk of death from heart disease, cancer, and other illnesses, according to a study conducted by NIA grantee Dr. Steven Blair and colleagues at the Institute for Aerobics Research in Dallas, Texas. The benefits of fitness were the same regardless of age, sex, or other risk factors.

The 13,344 men and women participants were asked about their medical history and given a physical exam. None of the volunteers had high blood pressure or diabetes, none had suffered a previous heart attack or stroke, and none had ECG abnormalities or abnormal treadmill test. They were assigned to physical fitness categories based on their age, sex, and the results of their treadmill test. During the 8-year follow-up, there were 238 deaths.

The investigators found that individuals who were not fit had a higher risk of dying from cardiovascular disease and cancer than those who were fit. Age-adjusted, all-cause death rates declined from 39.5 per 10,000 in the least-fit category of women to 8.5 per 10,000 in the group of women who were the most fit. Corresponding values were 64.0 per 10,000 in the least-fit category of men and 18.6 per 10,000 in the most-fit group of men. Based on these findings, the investigators estimate that if

all physically unfit persons became fit, death rates could be reduced by 15 percent in women and 9 percent in men.

In related research, the positive influence of exercise on delaying the onset of heart disease was found by NIA grantee Dr. Joel Posner and colleagues at the Medical College of Pennsylvania in Philadelphia.

Volunteers, age 60 to 86, recruited from senior centers in the Philadelphia area were given a physical exam, and detailed histories were taken. Volunteers were excluded from the study if they had any chronic diseases affecting their ability to exercise.

Participants were randomly assigned to three groups: long-term exercisers, short-term exercisers, and those who did not exercise (the control group). The first two groups rode a stationary bicycle for differing lengths of time. The control group attended weekly lectures.

After 4 months, the long-term group received bicycles to continue exercising at home. The short-term group was encouraged to continue exercising but not given home exercise equipment. The control group was told to carry on with their routine activities.

After 2 years, the investigators found that the control group had a significantly higher number of new heart conditions than either of the exercise groups, 12.9 percent compared to 2.4 percent for two exercise groups combined. Moreover, there was a significant difference in time to onset of newly diagnosed heart disease in the exercisers: the average time was 728 days for the long-term group and 715 days for the short-term group, compared to 672 days for the control group.

Dr. Posner believes that moderate exercise can improve fitness in healthy older people and that exercise provides some protection against the development of heart disease.

Dietary Restriction Retards Changes in Intestinal Cells

Scientists have found that animals fed as much food as they want are not as healthy and do not live as long as those whose diet is restricted in calories but formulated carefully to guard against malnutrition. To date, dietary restriction is the only intervention consistently shown to extend life span, and studies are under way to learn how it works.

NIA grantees Dr. Peter Holt of St. Luke's/Roosevelt Hospital Center and Columbia University in New York City, Dr. Arlan Richardson at the Audie L. Murphy VA Hospital and the University of Texas Health Science Center in San Antonio, and colleagues compared the cellular changes in the small intestines of two groups of rats--a control group fed an unrestricted diet and one

fed a diet that reduced calories while ensuring proper nutrition.

Examining the lining of the small intestines, Drs. Holt and Richardson found that the number of villus cells, tiny finger-like projections through which nutrients are absorbed and which secrete digestive juices, increased in control animals. In rats fed a restricted diet, villus cells were significantly increased only in the oldest rats.

Researchers also found a 61 percent increase in crypt cells at the base of the villi in the rats in the control group at 21 months compared to 12 months, and an 83 percent increase at 27 months. In rats with restricted diets, crypt cells did not increase until after 27 months of age. These data indicate that the increase in crypt cells--which is characteristic of the aging small and large intestines--was inhibited by restriction of food intake.

Dietary restriction prevented an increase in both villus and crypt cell numbers to the age of 27 months and beyond. This regimen also retarded similar proliferative changes in the colon. Scientists believe that an abnormal increase in the number of such cells is an important step in the development of cancer. The investigators showed that dietary restriction significantly retarded these intestinal changes and increased the life span of the animals.

Anti-Growth Gene Isolated

As they age, cells from animals and humans lose their capacity to proliferate. Intramural scientist Dr. David B. Danner and colleagues at the GRC have isolated a gene that codes for a protein termed prohibitin.

When Dr. Danner injected prohibitin messenger RNA into actively growing cells, the cells stopped growing but remained viable. This suggests that prohibitin, which may play a role in regulating normal cell growth, has an inhibitory effect on cell proliferation. Changes in the expression of the prohibitin gene also may play an important role in cellular senescence.

Dr. Danner believes that the discovery of a new antiproliferative gene may also be important to understanding the uncontrolled growth of cancer cells. When grown in culture, many types of cancer cells are immortal; that is, they escape normal cellular aging and continue to divide indefinitely. Changes in the expression of the prohibitin gene may be a key to why these cancer cells are able to continue their uninterrupted growth.

The scientists are now looking at the regulation of the prohibitin gene expression in normal, cancer, and aging cells. If overexpression of prohibitin is involved in age-related loss

of cell growth, then perhaps finding a way to control the expression of this gene will be important in minimizing age-related pathology.

New Research on Preventing Falls and Hip Fractures

Falls are the leading cause of injury-related disability and death among older people in this country. Every year falls result in more than 200,000 hip fractures and account for approximately \$7 billion in health care costs. Falls cause about 9,500 deaths annually among people 65 and older. Even if an injury does not result, a fall can lead to restricted activity and loss of mobility, confidence, and independence.

Former NIA intramural scientist Dr. Andrea Z. LaCroix and colleagues have shown that the use of the diuretic thiazide, which is prescribed for hypertension, is associated with a decrease in the incidence of hip fractures in older people.

Using data from the NIA's Established Populations for Epidemiologic Studies of the Elderly (EPSE), Dr. LaCroix analyzed data on hip fractures for 9,518 respondents over a 4-year period. The incidence rates for hip fractures among thiazide users was one-third less than that of non-users.

Although the number of hip fractures was higher for women than men, the protective effect of thiazide was apparent in both sexes. When other risk factors for hip fractures were considered, thiazide continued to have a protective effect. Using antihypertensive medications other than those containing thiazide diuretic agents was not associated with the risk of hip fracture in any of the three populations studied.

In a related study, NIA grantee Dr. Wayne A. Ray and colleagues at the Vanderbilt University School of Medicine in Nashville, Tennessee, showed that the risk of fall-related hip fractures can be reduced by eliminating or changing the type of tranquilizers prescribed for older people. Dr. Ray found that older people who took long-acting tranquilizers (those remaining in the body for 24 hours or longer) had a 70 percent greater risk of hip fracture than people who did not take psychotropic medications. Those taking short half-life medications had the same risk of hip fracture as people not taking benzodiazepines. The results were not influenced by complicating factors such as dementia, use of a cane or walker, assisted activities of daily living, nursing home residence, and previous hospitalization.

Long-acting tranquilizers cause a greater impairment of motor skills in older people than short-acting drugs, yet long half-life medications currently are prescribed in as many as 30 percent of geriatric cases. The effects of an evening dose of a long-acting tranquilizer on someone over 65 are likely to persist into the next day and in some cases can last several days.

Scientists Wake Up to Sleep Disorders in Older People

More than half the 29 million Americans over age 65 may experience disruptions of sleep, according to studies supported by NIA. These sleep disturbances may be caused by many factors, including ill health, retirement and changes in social patterns, death of a spouse or close friend, increased use of medications, and changes in circadian rhythms.

To assess current knowledge of sleep disorders in the aging population, NIA and NIH's Office of Medical Applications of Research sponsored a Consensus Development Conference on the treatment of sleep disorders in older people. Participants considered issues pertinent to diagnostic evaluation, use of medications, and education about sleep and sleep disorders. Although changes in sleep patterns have been viewed as part of the normal aging process, new information was presented indicating that many sleep disturbances are related to pathological processes associated with aging. A wide range of future studies was called for including research to develop diagnostic procedures and effective therapies for sleep apnea and insomnia--common sleep disorders among older persons.

The National Commission on Sleep Disorders Research held its first public hearing in September, 1990. Dr. William C. Dement at Stanford University's School of Medicine in California chairs the Commission; NIA's Dr. Andrew Monjan is the Executive Secretary. The Commission, established by the Department of Health and Human Services, will assess the extent to which sleep disorders exist and the social and economic consequences of sleep deprivation. It also will develop a national long-range plan to determine research and staffing needs relating to sleep disorders.

Social Factors Important for Those Living in Board and Care Homes

Many older people live in nursing homes and other institutions that are expensive and often physically and socially restrictive. For this reason, researchers are studying alternative living arrangements that may better meet the special needs of older adults.

Board and care homes (also called foster care or domiciliary care homes) are one such alternative. These facilities are usually private homes where a small group of unrelated adults live together. The owner of the home is, in most cases, an experienced caregiver. One advantage of board and care homes is that residents can receive help for a specific health problem yet live in a small, family-like atmosphere. In addition, on the average, costs are more affordable than at long-term care institutions. Board and care homes cost about \$450 a month, compared to about \$1,750 for one month in a nursing home.

NIA grantee Dr. J. Kevin Eckert and colleagues at the University of Maryland Graduate School in Baltimore interviewed 285 residents of board and care homes to learn more about how they operate, who lives in them, and the quality of care available. They found that the social aspects of the residents' environment, such as peer relationships, were significantly more important than their physical environment in producing the greatest sense of psychological well-being.

Participants were over age 60; 85 percent were white, 65 percent were women, and 67 percent were widowed. The only source of income for the majority of residents was their monthly Social Security payment. Residents were asked questions designed to gauge how comfortable they felt in their social and physical environment, the quality of relationships shared with other residents, the quality of personal care received from operators, and cost.

In general, participants felt that once their basic needs were met (i.e., an adequate physical environment, access to health care, and reasonable income), social factors were most important. Dr. Eckert cautions however that these findings must be viewed from the point of view of the population studied. Because of their small income, participants may have lacked information needed to compare different living arrangements.

Research on Aging Needed To Curb Cost of Care

Health care costs could triple in the next 50 years unless ways are found to prevent or delay the most debilitating illnesses affecting older people, according to a study by Dr. Edward L. Schneider at the University of Southern California's Andrus Gerontology Center and NIA intramural scientist Dr. Jack M. Guralnik. Using U.S. Census Bureau projections for the older population, the researchers analyzed the prevalence of disease and disability at specific ages and selectively estimated the costs of providing health care.

The Federal government's largest health care expenditure is through Medicare, which pays most health care costs for older Americans. The average Medicare cost per person increases with age, rising from \$2,017 per year for individuals age 65 to 74 to \$3,215 for those age 85 and above. According to Drs. Schneider and Guralnik, the cost of Medicare will nearly double by the year 2020. By 2040 the level of Medicare spending for the population age 65 and above could be as high as \$212 billion (in 1987 dollars) compared to \$71 billion in 1987.

Demographers agree that America's older population will increase dramatically during the next century. At the beginning of this century, only 4 percent of the population over age 65 was 85 or older. The Census Bureau now projects that by 2040 over 19 percent of this group will be 85 or older. The over-85 group, often called the oldest old, is the fastest growing segment of

the American population. According to this study, the cost of caring for the oldest old could rise from the \$9.2 billion spent in 1987 to as much as \$57.4 billion by 2040.

The researchers looked at two age-dependent disorders--dementia and hip fracture--that contribute significantly to disability, nursing home admissions, and the need for long-term care.

The prevalence of dementia, the most common form of which is Alzheimer's disease, increases rapidly with age. The growth of the oldest population group therefore could result in a three- to fivefold increase in the number of dementia patients, requiring as much as \$150 billion per year for their care.

Women age 85 and above are at particularly high risk for hip fracture. Approximately 20 percent of women who experience a hip fracture do not survive the first year; another 20 percent never regain the ability to walk without assistance. Drs. Schneider and Guralnik project that, without improved prevention efforts, the number of hip fractures could reach 840,000 a year, driving the cost of care up to \$6 billion annually.

As the population ages, escalating health care costs are of increasing concern to policy makers and individual families. Long-term solutions for projected increases in these costs must encompass more than cost-containment strategies. Drs. Schneider and Guralnik recommend that research resources be mobilized, just as research was set in motion to prevent polio. They suggest that long-term solutions will come from research that identifies ways to prevent the diseases and disorders that disable older persons.

National Cancer Institute

Cancer incidence increases with increasing age. Americans age 65 and over have ten times the risk of developing cancer than those under age 65; more than 50 percent of all cancers occur in the 12 percent of the population that is over age 65. The National Cancer Institute (NCI) uses the full range of its resources to address this important problem.

Cancer Incidence Rates for Older Americans Studied

The NCI intramural Surveillance Program, which collects statistics to measure the impact of cancer on the United States population to assess progress in cancer prevention and treatment, reported that the overall incidence rate for cancer in persons age 65 and older increased 1.4 percent for the years 1973 to 1987, the most recent period for which data have been evaluated. This increase is more than twice the 0.6 percent increase for people under 65 years during the same interval.

The mortality rate for many common cancers declined over the last 15 years, reducing the cancer death rate for white Americans under age 65. But for people over age 65, the overall mortality rate increased 13 percent. For most cancer sites, older Americans also experience poorer survival rates than the younger population.

Researchers Study Use of Mammograms By Older Women

NCI provided important technical assistance for a study conducted by the Jacobs Institute of Women's Health in Washington, D.C., which found that women are not getting mammograms as often as they should, and that women over age 65 are the least likely to do so. The survey of 980 American women age 40 and older examined use of mammography and attitudes towards this early detection procedure. About 65 percent of the women between age 60 and 69 had had a mammogram at some time in their lives. This is higher than a 1987 survey which showed only 38 percent had undergone the screening. However, only 24 percent of women age 60 to 69 have regular mammograms in accord with the guidelines developed by 13 national medical organizations, including NCI. These guidelines recommend that all women age 50 and over should have annual mammograms and a clinical breast exam and that women of all ages should perform monthly self-examinations.

National Heart, Lung, and Blood Institute

The National Heart, Lung, and Blood Institute (NHLBI) supports and conducts aging research related to normal function and diseases of the heart, blood vessels, lungs, and blood.

Alzheimer-Linked Protein Investigated

Amyloid protein deposits in the brain are usually associated with Alzheimer's disease and Down syndrome. The amyloid beta protein is derived from a large protein precursor, amyloid precursor protein. Granules in human platelets have been found to contain a large amount of the amyloid precursor protein and to release it when activated. NHLBI-supported investigators led by Dr. George Broze at Washington University School of Medicine in St. Louis, Missouri, have shown that this protein is an inhibitor of the blood coagulation Factor XIa, a deficiency of which is responsible for a mild to moderate degree of bleeding. Thus, amyloid precursor protein appears to play a role in the regulation of coagulation. Additional evidence of this relationship comes from studies of people with cerebral amyloid angiopathy, which is characterized by brain hemorrhages. A mutation in the genetic region coding for the amyloid precursor appears to be the primary defect in these patients.

Aging Heart Studied

It is well known that an older heart, when stimulated by beta-adrenergic agents, responds with a less forceful contraction than a young heart. Dr. James Dobson, an NHLBI grantee at the University of Massachusetts Medical School in Worcester, has observed that levels of adenosine, a body chemical that possesses anti-adrenergic properties, are greater in old than in young rat hearts. Dr. Dobson treated hearts from young and old rats with adenosine deaminase, an enzyme that destroys adenosine. He found that the increase in adenosine in older hearts was due neither to an increase in the activity of the enzyme responsible for the production of adenosine, nor to decreased adenosine deaminase activity. The reason for the increase in adenosine found in aged hearts remains to be elucidated.

Scientists Study Risk Factors for Heart Disease

The NHLBI-supported Cardiovascular Health Study, a 6-year, multicenter study of 5,201 community-based people age 65 or older, is investigating risk factors for heart disease and stroke. Early findings, reported by principal investigator Dr. Richard Kronnal at the University of Washington in Seattle, include a high frequency of impaired glucose tolerance (a measure of the body's ability to metabolize glucose), mild to moderate renal insufficiency, lower extremity arterial insufficiency, and abnormal cardiac function.

National Institute of Dental Research

The National Institute of Dental Research (NIDR) recently published its Long-Range Plan for the Nineties. This plan sets a high priority on the oral health of adults and older Americans.

Unique Program Fosters Research and Action

The NIDR Research and Action Program to Improve the Oral Health of Older Americans and Other Adults at High Risk serves as an umbrella for a wide range of activities involving collaboration with many public and private organizations. NIDR is guiding the research component. An Oral Health Coordinating Committee has been established for Public Health Service agencies, contracts have been awarded for epidemiological and prevention studies, and funds have been provided to establish a consortium of public and private groups to facilitate health promotion.

Scientists Track Downward Trend in Caries

NIDR intramural researchers Drs. L. Jackson Brown and Philip A. Swango reported that, for the first time, the mean number of decayed, missing, and filled teeth has declined among American, employed adults age 18 to 44 years old. These improvements, shown in 1985 survey data, are reported for all teeth, in both males and females, and for all regions of the country. This downward trend is expected to have a major, positive impact on the oral health status of older adults in years to come.

Most Oral Senses Do Not Change with Age

NIDR intramural scientists Drs. James Weiffenbach, Carolyn Tylanda, and Bruce Baum studied oral sensitivity to several types of taste and nontaste stimuli in 87 healthy men and women between age 25 and 93. Differences in perception of taste (sugar and salt), temperature (heated or chilled water), pressure (local pressure on the back of the tongue), and viscosity (water thickened with methylcellulose) were measured. Age had no significant effect except on the perception of pressure, which declined significantly with age.

In another intramural study, Drs. Jonathan Ship, Philip Fox, and Bruce Baum demonstrated a great variation in flow rates from the salivary glands of healthy, unmedicated individuals of different ages, suggesting that comparison of individual flow rates against a population standard is an unreliable indicator of salivary dysfunction.

National Institute of Diabetes and Digestive and Kidney Diseases

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) conducts and supports research into the causes, treatment, and prevention of many of the chronic and disabling diseases affecting public health. Among some of the diseases under study that disproportionately affect older people are osteoporosis and benign prostatic hyperplasia.

Researchers Shed Light on Vitamin D Receptors

Vitamin D is a steroid hormone-like molecule that stimulates calcium absorption and directly affects bone. Recent studies by NIDDK intramural researchers Dr. Stephen Marx and colleagues focus on the way vitamin D activates its receptors. Like receptors for other steroid hormones, the receptors for vitamin D are within the cell rather than on the cell surface. It has long been thought that these receptors sit on the cell's DNA, waiting to be turned on. The NIDDK scientists, using a method they developed to prepare (fix) cells so that receptor activation can be visualized, have now discovered that the receptors do not reside on the DNA in the cell nucleus but rather are dispersed in the cell's cytoplasm. When vitamin D is added to the cells, however, the receptors rapidly clump and move into the cell nucleus.

The fixation method, which is based on the use of microwave irradiation, also allowed the researchers to observe the activity of cGMP, a second messenger involved in the action of vitamin D and other hormones. They found that, in response to vitamin D activation, cGMP increases and accumulates around the vitamin D receptors.

Growth Factor Plays a Role in Prostate Growth

Benign prostatic hyperplasia (BPH), or prostate enlargement, is a common disorder affecting older men, with 400,000 surgeries performed each year to relieve its symptoms. Researchers know that prostate growth begins in men in their 20's and 30's but usually does not cause symptoms until age 50 or older. Recent studies have focused on factors that regulate growth in the hope of identifying factors that initiate abnormal growth.

Studies by Dr. John Grayhack and associates at the NIDDK-supported George M. O'Brien Kidney and Urologic Diseases Research Center at Northwestern University in Chicago, Illinois, have shown that, in addition to male sex hormones (androgens), the rat testes secrete a substance that plays a role in enhancing the androgen-stimulated growth of the prostate. In related studies, NIDDK grantee Dr. Russell Lawson and colleagues at the Medical College of Wisconsin in Milwaukee, using human prostate cells grown in culture, have found that specific substances called growth factors can inhibit or enhance the growth of cells derived from the human prostate.

These findings provide new insights into the long-held theory that prostate growth and the development of BPH are regulated solely by male sex hormones and paves the way for developing agents to regulate and arrest prostate cell growth before the symptoms of BPH appear.

National Institute of Neurological Disorders and Stroke

Aging research at the National Institute of Neurological Disorders and Stroke (NINDS) focuses on several nervous system disorders that diminish the quality of later life. Current programs include studies of Parkinson's disease, Alzheimer's disease, and stroke, all neurological problems that become increasingly common as people age. (NINDS research on Alzheimer's disease is described in a separate report.)

New Theory for Parkinson's Disease Tested

More than half a million people in the United States, most of them over age 60, have Parkinson's disease, which causes tremors, rigidity, and difficulty with speech and movement that can make even simple tasks impossible. NINDS scientists are concentrating their efforts on finding the cause(s) and improving treatments.

Dopamine is one of several chemical messengers in the brain that helps transmit signals from one nerve to another. In a normally functioning brain, dopamine acts as a neurotransmitter to regulate electrical activity in the nerve cells of the motor system. It is produced in the region of the brain called the substantia nigra but in Parkinson's disease, nerve cells in the substantia nigra die off prematurely, reducing the levels of dopamine. While a majority of investigators have focused on studies of the substantia nigra, some researchers have theorized that other parts of the brain may be involved in this process.

A preliminary study indicates that the rigidity and tremors symptomatic of Parkinson's disease may be associated with excessive activity in the part of the brain called the subthalamic nucleus. NINDS grantee Dr. Mahlon DeLong and colleagues, formerly of The Johns Hopkins University School of Medicine in Baltimore, Maryland, and currently at Emory University in Atlanta, Georgia, report that two MPTP-treated monkeys demonstrated marked improvement of Parkinson-like symptoms when injected with a chemical that killed the nerve cells in the subthalamic nucleus.

Experimental reduction of dopamine production with MPTP results in overactivity of nerve cells in the subthalamic nucleus and produces the tremors and rigidity characteristic of Parkinson's disease. Dr. DeLong showed that destroying this now-unregulated region of the brain resulted in a reversal of Parkinson symptoms. The study contributes to a better understanding of dopamine in brain functioning.

Drugs Delay Disease Progress

In a continuing clinical trial, NINDS grantee Dr. Ira Shoulson at the University of Rochester in New York is studying the drugs deprenyl and tocopherol in treating Parkinson's

patients. The progress of early-stage Parkinson's disease was significantly delayed up to 10 to 12 months in the groups receiving deprenyl alone or in combination. These results were so significant that participants were regrouped after just 9 months (rather than the proposed 5-year study period) so that all patients would receive some form of deprenyl. Further study will test the long-term effects of deprenyl and the value of tocopherol in combination with deprenyl.

National Institute of Allergy and Infectious Diseases

For many people over 65 years old, influenza can result in extended hospitalizations and even death. Immunization against influenza has been universally recommended for this population. The National Institute of Allergy and Infectious Diseases (NIAID) conducts and supports research on the biology of many of the organisms that cause viral infections such as influenza.

Live-Virus Vaccines Protect Against Influenza

NIAID contractors Drs. John J. Treanor and Robert F. Betts and colleagues at the University of Rochester Medical Center in New York evaluated the combination of a live cold-adapted influenza A vaccine with an inactivated flu vaccine in 151 nursing home residents aged 66 to 102 (average age 80). Influenza A is the most prevalent type of flu. Residents of nursing homes are at special risk for influenza because they often have chronic medical conditions that increase susceptibility to infection and possible complications. They are also in a closed environment that fosters transmission of some infectious diseases.

Live-virus vaccines are thought to provide more complete and long-lasting protection than the more commonly used inactivated vaccines, but they carry the risk of causing symptoms of the illness they are intended to prevent. Live cold-adapted influenza vaccines consist of live virus that is less virulent and weakened or "attenuated" into a formula that serves as a safe yet protective vaccine for humans. Unlike inactivated influenza vaccines, which are given in intramuscular injections, the live influenza vaccine is administered through nose drops.

In the nursing home study, all participants received the inactivated vaccine plus either the live vaccine or a placebo. The live vaccine caused no significant ill effects. During a subsequent outbreak of influenza A, residents who had received both vaccines had lower rates of influenza illness, characterized by fever and upper respiratory symptoms such as cough, than did the recipients of the inactivated vaccine alone. Researchers concluded that a combination of live and inactivated vaccines may provide greater protection than inactivated vaccine alone against influenza A in nursing home populations.

National Eye Institute

Age-related eye diseases threaten the quality of life for many older Americans. In fact, half of this country's visually impaired citizens are 65 or older. Although older people currently account for one-third of all visits for medical eye care, research advances have improved the chance of maintaining good visual health well into retirement. The National Eye Institute (NEI) supports a major research effort to reduce the burden of aging-related eye diseases.

Laser Surgery Tried as a First-Line Glaucoma Treatment

Glaucoma is the second leading cause of blindness among all Americans and the leading cause of blindness among African Americans. Of the 4,600 people who become blind from glaucoma each year, the vast majority suffer from open-angle glaucoma, in which microscopic changes in the eye interfere with the flow of fluids that nourish tissues in the front of the eye. When these fluids fail to drain properly, increased pressure inside the eye can slowly damage the optic nerve.

Eye specialists usually treat newly diagnosed glaucoma patients with eyedrops, either to improve fluid drainage or to slow fluid formation. If drops alone do not bring the eye pressure to an acceptable level, the physician may use laser surgery to create a tiny hole in the coat of the eye or stretch open holes in the drainage tissue. Some doctors have begun to use lasers for the initial treatment of glaucoma.

Although there are advantages and disadvantages to both forms of treatment, the two have not been compared under controlled conditions. To do this, NEI funded the Glaucoma Laser Trial, a randomized, controlled clinical study.

To ensure that one eye of each study participant would receive the better treatment, all 271 participants received both methods, one in each eye. If the initial treatment with either laser surgery or medicated eyedrops failed to control ocular pressure, additional eyedrops were administered according to a stepped sequence, progressing from milder to stronger eyedrops or combinations.

After 2 years, the researchers found that laser treatment alone resulted in pressure control in 44 percent of the participants' eyes. Pressure was controlled in 30 percent of the eyes treated with the mildest eyedrop, timolol. When timolol was used after laser treatment, pressure was controlled in 70 percent of the eyes. When eyes in either treatment group required stronger eyedrops, pressure was controlled in 89 percent of those having prior laser treatment and in 66 percent of those who received only medication.

Participants will be followed for an additional 3 years to determine if lasers are a safe and effective alternative to eyedrops as a first line of treatment.

National Institute of Environmental Health Sciences

The National Institute on Environmental Health Sciences (NIEHS) conducts basic and applied research into aging processes and how environmental factors influence aging. Cellular mechanisms of aging, the effects of chemicals on cellular repair, and diseases related to aging are investigated by intramural scientists and NIEHS grantees.

Genetic Basis of Aging Studied

NIEHS intramural scientists Dr. Osamu Sugawara, Lois Annab, and Dr. J. Carl Barrett studied genetic factors related to aging cells in culture. Normal human fibroblast/syrian hamster cell hybrids have limited life span in culture before they cease growing (senescence). The NIEHS team discovered that those hybrid cells missing copies of human chromosome 1 were immortal. Reintroduction of human chromosome 1 caused these cells to act like normal cells and stop growing. These studies indicate that defects in genes on human chromosome 1 are involved in senescence and cancer. Efforts in progress to clone senescent genes may lead to new insights into both cancer and aging processes.

Scientists Look at Environmental Issues

NIEHS grantee Dr. Jane Q. Koenig at the University of Washington in Seattle, is studying the effects of sulfur dioxide on lung function in people over age 55. Previous epidemiologic data indicate that older people are at risk for developing lung disease or even dying during periods of poor air quality. Dr. Koenig is determining whether age alone makes a person more susceptible to the effects of inhaled air pollutants.

NIEHS-supported scientists are also conducting studies to determine whether the continuing depletion of the protective ozone layer of the atmosphere will lead to increased human exposure to ultraviolet (UV) radiation. Known effects of UV radiation in humans include skin cancers and immunosuppression. In addition, studies of UV radiation in mice have revealed that, as the dose increases, the life span of the mice shortens. It is not clear that the same effect would occur in humans, but additional studies are being conducted in other mammals and animals.

Dr. Ronald D. Ley at the Lovelace Medical Foundation in Albuquerque, New Mexico, is also studying the effects of chronic UV radiation. His studies are using the South American opossum because its repair capabilities are very similar to those of humans. Results from these experiments and others will enable scientists to evaluate the life-shortening potential of UV radiation.

National Institute of Arthritis and Musculoskeletal
and Skin Diseases

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) places a high priority on research on the musculoskeletal problems faced by an aging population. These include osteoporosis, osteoarthritis, and Paget's disease.

Advances Made in the Prevention and Treatment of Osteoporosis

NIAMS leads and coordinates biomedical research to improve the diagnosis, treatment, and prevention of osteoporosis. The Institute sponsors basic research on bone biology and bone metabolism, funds Specialized Centers of Research (SCORs) on osteoporosis, conducts clinical trials, and performs educational research.

As part of its mandate, in February, 1990, NIAMS cosponsored a conference with NIA, NIDDK, the National Osteoporosis Foundation, and the American Society for Bone and Mineral Research on research advances in osteoporosis. A report summarizing the participants' recommendations and the state of the art in osteoporosis research will soon be published.

NIAMS grantee Dr. Robert Lindsay at the Helen Hayes Hospital in West Haverstraw, New York, one of three SCORs on osteoporosis, conducted a 2-year controlled study confirming the usefulness of estrogen in treating women with postmenopausal osteoporosis. Research revealed that in these women, oral estrogen supplemented by calcium increased bone mass in the spine by 10.6 percent and in the hip by 5.5 percent.

In a study of bone mineral density in the upper thigh bone of 263 women age 20 to 84, NIAMS grantee Dr. J.C. Gallagher at Creighton University Medical School SCOR in Omaha, Nebraska, found that during the first 6 years after menopause, the decrease in bone mineral density was 3 to 10 times more than in the decade prior to menopause. These findings underscore the importance of starting estrogen replacement therapy right after menopause.

In postmenopausal osteoporosis, poor absorption of calcium, the chief mineral substance in bone, is often associated with reduced blood levels of 1,25-dihydroxyvitamin D. Dr. Gallagher and NIAMS grantee Dr. B. Lawrence Riggs at the Mayo Clinic in Rochester, Minnesota, recently reported that treatment twice daily with a vitamin D analog improves calcium absorption and reduces the spinal fracture rate.

Because sodium fluoride builds bone mass, it once was thought to be an answer for treating osteoporosis. Clinical trials led by Dr. Riggs and NIAMS grantee Dr. Michael Kleerekoper at Henry Ford Hospital in Detroit, Michigan, found that sodium fluoride increases bone mass in the spine but produces bone that is still susceptible to fracture.

National Institute on Deafness and Other Communication Disorders

The National Institute on Deafness and Other Communication Disorders (NIDCD) conducts and supports research and research training on normal hearing and on disorders of hearing and other communication processes. The Institute studies diseases affecting hearing, balance, smell, taste, voice, speech, and language.

Scientists Study Presbycusis

Many individuals beyond age 50 lose some hearing ability each year. The decline is gradual and progressive so that by age 60 or 70 as many as 25 percent of older persons are noticeably hearing impaired. One form of hearing loss affecting older persons is sensorineural hearing loss. Sound is transmitted efficiently through the external and middle ears, but parts of the inner ear or auditory nerve may be damaged or destroyed. Presbycusis is a common type of sensorineural hearing loss in older people. In presbycusis, changes in the inner ear lead to difficulties in understanding speech, and possibly an intolerance for loud sounds, but not total deafness. Symptoms of presbycusis are different in each person, suggesting a genetic predisposition. Presbycusis is usually attributed to aging but, because it does not affect everyone, some investigators view it as a disease. Environmental noise, certain medications, improper diet, and genetic make-up may contribute to this disorder.

In the past, it was believed that hearing loss in aging was largely the result of a cumulative loss of hair cells in the cochlea, noise exposure, and genetic predisposition. However, Dr. Donald Casary and colleagues at Southern Illinois University School of Medicine in Springfield, have found that neurochemical faults may underlie certain auditory processing disorders found in presbycusis. This is one of a number of NIDCD-funded studies that suggest that aging-related loss of neurotransmitters occurs in some auditory brain structures but not in others. Research is now in progress to correlate age-related loss of specific auditory functions with alterations in neurotransmitter function.

Other NIDCD-supported scientists are investigating the interaction between the hearing loss produced by repeated, lifelong exposure to noise (including occupational noise) and the hearing loss associated with aging. NIDCD and the NIH Office of Medical Applications of Research sponsored a Consensus Development Conference on noise and hearing loss in January, 1990. Dr. John Mills, at the Medical University of South Carolina in Charleston, reported that most of the data on presbycusis comes from clinical or epidemiologic studies. The data suggest that a significant portion of age-related hearing loss seems to be the result of exposure to noise rather than a consequence of aging. Mills notes that only recently has an animal model been available for the study of presbycusis.

National Center for Research Resources

Shared facilities provided by the National Center for Research Resources (NCRR) support a variety of studies focused on aging. Recently, grantees of the General Clinical Research Centers (GCRC) program found that a drug used to treat breast cancer also may increase bone mass in women who are susceptible to osteoporosis. Other GCRC grantees have documented the effect of stomach acid on absorption of drugs in older people.

Breast Cancer Drug May Prevent Osteoporosis

A drug used to treat breast cancer may protect against osteoporosis, according to NCRR grantee Dr. Ethel Siris at the Columbia-Presbyterian Medical Center GCRC in New York City. She found that the drug tamoxifen may mimic estrogen in bone cells and help prevent bone loss. In breast cancer cells, tamoxifen appears to have the opposite effect, inhibiting the cancer-promoting effects of estrogen.

Dr. Siris notes that estrogen stimulates growth of tumors in about 70 percent of postmenopausal breast cancer patients. Tamoxifen, a widely accepted breast cancer therapy, binds with estrogen receptors on tumor cells and thereby blocks the action of estrogen.

Physicians had worried that tamoxifen would block the protective effects of estrogen on bone tissue, leading to osteoporosis. But Dr. Siris and colleagues, studying bone density in ten breast cancer patients who had been taking tamoxifen twice daily for 1 year, found that bone mass showed a slight overall increase during the 1-year study. A matched group of patients who did not take tamoxifen showed a significant decrease. The investigators are expanding their research with a 5-year study of tamoxifen's potential for preventing osteoporosis.

Low Stomach Acid Slows Drug Absorption

Many older people have a lower level of acidity in the stomach than do young people, according to NCRR grantee Dr. Jennifer B. Dressman at the University of Michigan GCRC in Ann Arbor. Because the stomach acidity level can affect the absorption of certain drugs, Dr. Dressman and colleagues believe that many older people may require an adjustment in the dose or selection of drugs prescribed for them.

In a study of 80 healthy older people, Dr. Dressman found that about 10 percent of them experienced excessively low stomach acid levels both before and after meals. Another 40 percent of the participants needed an abnormally long time for stomach acid levels to return to normal after meals. In those with poor gastric acid secretion, drug absorption rates were significantly lower than in older participants with unimpaired acid secretion.

Dr. Dressman estimates that as many as 2 million Americans over age 65 might need adjustments in their prescriptions. Absorption rates would be especially important for some orally administered cardiovascular and blood pressure medications, calcium supplements, and antifungal drugs.

National Center for Nursing Research

The National Center for Nursing Research (NCNR) interest in aging focuses on the causes of mental and physical dysfunction in older Americans, and on better ways to help them maintain their physical and mental abilities.

Muscle Strength Exercises Combat Urinary Incontinence

Pelvic muscle exercises often are prescribed to prevent or treat urinary incontinence (UI). Earlier reports of success in controlling UI have varied depending on the techniques used, the type of UI, and the age or health of the study participants.

While UI is a common problem in older women, it also is found in younger women, particularly following childbirth. NCNR grantee Dr. Molly Dougherty and colleagues at the University of Florida College of Nursing in Gainesville designed a study to determine the optimum intensity and duration of pelvic muscle exercises needed to significantly increase pelvic muscle strength in healthy, reproductive-age women. Using principles of exercise physiology, the investigators prescribed exercises that emphasize gradual, sustained effort. The 48 women in the study performed the exercises every other day, gradually increasing both number and duration.

This protocol, the investigators found, led to significantly improved pelvic muscle strength. In addition, improvement occurred with much lower levels of exercise than had previously been reported in the literature. The investigators will now consider how this regimen will work in an older population.

Outlook

We experience the impact of aging daily--as we watch ourselves grow and change and as we assist our aging family members. These profound personal changes ripple outward to our society as a whole. And, as our society increasingly ages, these issues take on a greater importance at the national level.

NIH conducts and supports research that affects our understanding of aging processes as well as our ability to assure this country's citizens a healthy and independent old age. Success in these research efforts promises science and society alike some of the most exciting frontiers of the decade.

Health Care Financing Administration

HEALTH CARE FINANCING ADMINISTRATION

Services to the AgedA. Medicaid Program

Title XIX contains several provisions directed primarily to those persons aged 65 or over: payment of Medicare premium, copayment, and deductible amount (for each assistance recipient); and coverage of inpatient hospital services in institutions for mental diseases. Long term care services, including nursing facility services used primarily by the aged, as well as prescription drugs, eyeglasses, and hearing aids, may also be covered by Medicaid.

The aged amount to a significant portion of Medicaid expenditures. About 32 percent of Medicaid program dollars will be spent on care for the aged in FY 1992, and it is estimated that 3.6 million people over age 65 (or about 13 percent of all recipients) will receive health care services. For most of these persons, Medicaid provides services which supplement and complement those provided by Medicare.

B. Medicare Program

In FY 1992, about 34.8 million persons will be covered under Medicare. Of these, 31.4 million will be persons aged 65 or over, and 3.4 million will be under age 65 but disabled. Within this Medicare-covered group, Hospital Insurance beneficiaries are protected against the costs of inpatient hospital services, nursing facility services, home health services and hospice care. The voluntary Supplementary Medical Insurance program generally covers the cost of specific physician and physician-related services. Both parts of the Medicare program provide payment for the covered health services subject to certain deductibles and coinsurance amounts.

Under current law, Hospital Insurance program benefit payments for FY 1992 are expected to total \$76.2 billion, while Supplementary Medical Insurance benefit payments are expected to be \$50.6 billion.

Social Security Administration

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Social Security Administration

Aging

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II. SUPPLEMENTAL SECURITY INCOME BENEFITS AND BENEFICIARIES

On January 1, 1991, SSI payment levels increased by \$21.00 for an individual and \$31.00 for a couple. Thus, beginning in January 1991, maximum monthly Federal SSI payment levels increased from \$386.00 to \$407.00 for an individual, and from \$579.00 to \$610.00 for an eligible couple.

During fiscal year 1990 nearly \$14.4 billion in benefits (consisting of \$11.5 billion in Federal funds and \$2.9 billion in federally-administered State supplements) were paid. Of 4.8 million beneficiaries on the rolls during September 1990, 1.5 million were aged, and 3.3 million were receiving SSI based on blindness or disability, although 597,500 of those in the latter category reached age 65 after they began receiving payments.

III. BLACK LUNG BENEFITS AND BENEFICIARIES

For September 1990, about 212,000 individuals received \$71 million in black lung benefits which were administered by the Social Security Administration. These benefits are financed from general revenues. Of these individuals, 83,000 miners received \$23.7 million, while 129,000 widows and children not in the custody of a miner or entitled widow received \$47.3 million.

Black lung benefits increased by 4.1 percent in January 1991 due to an automatic general benefit increase adjustment under the law. The monthly payment to a coal miner disabled by black lung disease is \$387.10. The monthly benefit for a miner or widow with one dependent is \$580.70 and with two dependents is \$677.40. The maximum monthly benefit payable when there are three or more dependents is \$774.20.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

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(In Millions of Dollars)

	1988 1/ <u>Actual</u>	1989 <u>Actual</u>	1990 <u>Actual</u>	1991 <u>Estimate</u>	1992 <u>Estimate</u>
IV. Social Security Administration					
<u>Payments to Persons</u>					
<u>Age 65 and Over From</u>					
<u>Federal General Revenue</u>					
<u>Funds:</u>					
Supplemental Security Income Payments . .	\$4,433	\$4,360	\$3,897	\$5,132	\$5,154
Special Benefits for Disabled Coal Miners	<u>826</u>	<u>808</u>	<u>793</u>	<u>777</u>	<u>757</u>
Subtotal, Payments to Persons Age 65 and Over from General Revenue Funds . . .	\$5,259	\$5,168	\$4,690	\$5,909	\$5,911
<u>Benefit Payments to</u>					
<u>Persons Age 65 and</u>					
<u>Over from Social</u>					
<u>Security Trust Funds</u>	<u>\$165.993</u>	<u>\$175.240</u>	<u>\$188.729</u>	<u>\$203.750</u>	<u>\$218.633</u>
Total, Social Security Administration . . .	\$171,252	\$180,408	\$193,419	\$209,659	\$224,544

1/ Due to Federal legislation mandating check payment on a banking day, the SSI program made 13 monthly payments in FY 1988, 11 monthly payments in FY 1990, and will make 12 monthly payments in the other years.

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Social Security Administration

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III. BLACK LUNG BENEFITS AND BENEFICIARIES

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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Funds for Programs to the Aged FY 1988 - FY 1992
(In Millions of Dollars)

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IV. Social Security Administration					
<u>Payments to Persons</u> <u>Age 65 and Over From</u> <u>Federal General Revenue</u> <u>Funds:</u>					
Supplemental Security Income Payments . .	\$4,433	\$4,360	\$3,897	\$5,132	\$5,154
Special Benefits for Disabled Coal Miners	<u>826</u>	<u>808</u>	<u>793</u>	<u>777</u>	<u>757</u>
Subtotal, Payments to Persons Age 65 and Over from General Revenue Funds . . .	\$5,259	\$5,168	\$4,690	\$5,909	\$5,911
<u>Benefit Payments to</u> <u>Persons Age 65 and</u> <u>Over from Social</u> <u>Security Trust Funds</u>	<u>\$165,993</u>	<u>\$175,240</u>	<u>\$188,729</u>	<u>\$203,750</u>	<u>\$218,633</u>
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DEPARTMENT OF HEALTH AND HUMAN SERVICES
Social Security Administration

Aging

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III. BLACK LUNG BENEFITS AND BENEFICIARIES

For September 1990, about 212,000 individuals received \$71 million in black lung benefits which were administered by the Social Security Administration. These benefits are financed from general revenues. Of these individuals, 83,000 miners received \$23.7 million, while 129,000 widows and children not in the custody of a miner or entitled widow received \$47.3 million.

Black lung benefits increased by 4.1 percent in January 1991 due to an automatic general benefit increase adjustment under the law. The monthly payment to a coal miner disabled by black lung disease is \$387.10. The monthly benefit for a miner or widow with one dependent is \$580.70 and with two dependents is \$677.40. The maximum monthly benefit payable when there are three or more dependents is \$774.20.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Funds for Programs to the Aged FY 1988 - FY 1992
(In Millions of Dollars)

	1988 ^{1/} <u>Actual</u>	1989 <u>Actual</u>	1990 <u>Actual</u>	1991 <u>Estimate</u>	1992 <u>Estimate</u>
IV. Social Security Administration					
<u>Payments to Persons</u>					
<u>Age 65 and Over From</u>					
<u>Federal General Revenue</u>					
<u>Funds:</u>					
Supplemental Security Income Payments . .	\$4,433	\$4,360	\$3,897	\$5,132	\$5,154
Special Benefits for Disabled Coal Miners	<u>826</u>	<u>808</u>	<u>793</u>	<u>777</u>	<u>757</u>
Subtotal, Payments to Persons Age 65 and Over from General Revenue Funds . . .	\$5,259	\$5,168	\$4,690	\$5,909	\$5,911
<u>Benefit Payments to</u>					
<u>Persons Age 65 and</u>					
<u>Over from Social</u>					
<u>Security Trust Funds</u>	<u>\$165,993</u>	<u>\$175,240</u>	<u>\$188,729</u>	<u>\$203,750</u>	<u>\$218,633</u>
Total, Social Security Administration . . .	\$171,252	\$180,408	\$193,419	\$209,659	\$224,544

1/ Due to Federal legislation mandating check payment on a banking day, the SSI program made 13 monthly payments in FY 1988, 11 monthly payments in FY 1990, and will make 12 monthly payments in the other years.

ACQUIRED IMMUNODEFICIENCY SYNDROME

	Obligations				
	1988 Actual 1/	1989 Actual 1/ 3/	1990 Actual 1/ 5/	1991 Estimate	1992 Estimate
HEALTH AND HUMAN SERVICES					
PUBLIC HEALTH SERVICE					
National Institutes of Health:					
National Institute of Allergy and Infections Diseases.....	\$223,298,000	\$311,277,000	\$394,088,000	\$433,610,000	\$459,339,000
National Cancer Institute.....	89,944,000	122,247,000	149,299,000	159,834,000	169,046,000
National Heart, Lung and Blood Institute...	24,885,000	38,088,000	42,056,000	43,391,000	43,668,000
National Institute of Dental Research.....	3,850,000	3,920,000	4,662,000	6,496,000	6,918,000
National Institute of Diabetes and Digestive and Kidney Diseases.....	3,330,000	3,557,000	5,306,000	5,906,000	6,497,000
National Institute of Neurological Disorders and strokes.....	12,342,000	13,069,000	16,158,000	16,312,000	17,552,000
National Institute of General Medical Sciences.....	7,724,000	10,830,000	14,614,000	15,587,000	16,320,000
National Institute of Child Health and Human Development.....	17,153,000	22,437,000	26,749,000	31,016,000	34,666,000
National Eye Institute.....	3,830,000	4,828,000	3,333,000	5,680,000	5,982,000
National Institute of Environmental Health Sciences.....	3,896,000	4,138,000	4,258,000	4,516,000	4,754,000
National Institute on Aging.....	361,000	443,000	859,000	907,000	1,007,000
National Institute of Arthritis and Musculoskeletal and Skin Diseases.....	361,000	673,000	1,238,000	1,635,000	1,736,000
National Institute on Deafness and Communication Disorders.....	---	---	---	649,000	706,000
National Center for Research Resources.....	28,283,000	67,565,000	46,147,000	47,496,000	50,231,000
National Center for Nursing Research.....	602,000	702,000	987,000	2,857,000	3,036,000
John F. Fogarty International Center.....	4,503,000	4,619,000	4,898,000	3,331,000	3,622,000
National Library of Medicine.....	---	20,000	493,000	519,000	1,063,000
Office of the Director.....	3,636,000	12,863,000	10,284,000	13,103,000	13,889,000
Buildings and Facilities.....	370,000	5,772,000	12,880,000	9,502,000	7,000,000
Total, National Institutes of Health.....	430,370,000	627,050,000	740,509,000	804,567,000	851,232,000
	2/	4/			
Food and Drug Administration.....	30,873,000	73,773,000	37,428,000	63,236,000	72,302,000
Centers for Disease Control.....	304,942,000	377,592,000	442,812,000	494,660,000	494,660,000
Alcohol, Drug Abuse, and Mental Health Administration...	112,257,000	173,336,000	213,814,000	236,304,000	244,776,000
Health Resources and Services Administration.	36,936,000	59,932,000	112,467,000	265,915,000	265,915,000
Office of the Assistant Secretary of Health..	4,046,000	6,405,000	6,562,000	8,238,000	8,773,000
Indian Health Service.....	---	800,000	2,670,000	1,803,000	1,803,000
Agency for Health Care Policy and Research...	1,033,000	6,830,000	8,470,000	10,252,000	10,800,000
Total Public Health Service.....	920,679,000	1,325,720,000	1,584,732,000	1,885,175,000	1,950,261,000

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ACQUIRED IMMUNODEFICIENCY SYNDROME

Obligations

	1988 Actual 1/	1989 Actual 1/ 3/	1990 Actual 1/ 5/	1991 Estimate	1992 Estimate
HEALTH AND HUMAN SERVICES - OTHER					
Health Care Financing Administration.....	360,000,000	545,000,000	780,000,000	1,050,000,000	1,360,000,000
Social Security Administration.....	98,000,000	153,000,000	219,000,000	305,000,000	439,000,000
Office of Civil Rights.....	---	2,700,000	3,365,000	3,365,000	3,365,000
Total, Health and Human Services.....	1,378,679,000	2,026,420,000	2,587,097,000	3,243,540,000	3,752,626,000

1/ Reflects obligations and does not tie to history appropriation tables.

2/ Includes supplemental appropriation of \$5,500,000 for blood safety.

3/ Includes \$23,884,000 in MCRR and \$872,000 in B&F of no-year money which was obligated in FY 1989.

4/ Includes \$22,500,000 for building construction.

5/ Includes \$51,000 in no-year carry over funds in MCRR that was re-obligated in FY 1990.

National Institutes of Health

Acquired Immunodeficiency Syndrome

The many areas of research supported by the National Institutes of Health (NIH) continue to expand scientific knowledge of the cause of the acquired immunodeficiency syndrome, or AIDS, and its treatment and prevention. Basic AIDS research continues to increase understanding of the structure and behavior of the human immunodeficiency virus (HIV) and the body's response to it. Epidemiologic information concerning the transmission of HIV and the natural history of HIV infection is being collected worldwide. The past year has also seen important steps forward in preclinical and clinical research into new therapies for AIDS, while exciting advances have increased hope that a safe and effective vaccine against AIDS is possible. Moreover, the investment in AIDS has benefitted science broadly, contributing substantially to the fields of virology, immunology, microbiology, and molecular biology, as well as drug and vaccine development.

This research is being conducted through intramural studies, grants, collaborative agreements, and contracts. The National Institutes of Allergy and Infectious Diseases (NIAID) leads the NIH AIDS research effort, with major contributions by the National Cancer Institute (NCI), the National Heart, Lung and Blood Institute (NHLBI), the National Institute of Child Health and Human Development (NICHD), and the National Center for Research Resources (NCRR). The National Institute of Dental Research (NIDR), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of General Medical Sciences (NIGMS), the National Eye Institute (NEI), the National Institute of Environmental Health Sciences (NIEHS), the National Institute on Aging (NIA), the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), the National Center for Nursing Research (NCNR), the Fogarty International Center (FIC), and the Office of the Director, NIH, are also conducting or supporting AIDS research. Moreover, many individuals infected with HIV have participated in studies of experimental AIDS therapies at the Clinical Center. The National Library of Medicine (NLM) provides online AIDS-related databases to keep physicians, scientists and others abreast of the rapidly expanding information in this area.

Basic Biology of HIV Infection

AIDS is characterized by the loss of essential cells of the immune system known as T4 lymphocytes. T4 cells are instrumental in regulating the immune system, which protects the body from invasion by infectious agents or from the emergence of certain tumor cells. Because HIV infection destroys the body's ability to defend itself against other invading microbes, many AIDS patients die of so-called opportunistic infectious (OIS)--those

that take advantage of a weakened immune system.

HIV gains entry into T4 cells by attaching to a molecule called CD4 that is present on the surface of these cells. Proteins on the exterior envelope of the virus bind tightly to the CD4 molecule; HIV then enters the cell by fusing to the cell's membrane. Once inside, HIV hijacks the cell's genetic machinery, using it to reproduce more viruses. Equipped with an enzyme called reverse transcriptase (RT), HIV transcribes its own genetic material, RNA (ribonucleic acid), into DNA (deoxyribonucleic acid). Because HIV converts its genetic material "backwards" from the normal route for cells and many viruses, it is known as a retrovirus. The genetic material from the virus, now in the form of DNA, then inserts itself somewhere in the genome of the host cell; once there, it is called a provirus.

Once integrated into the host cell's genetic material, the provirus may lie dormant for long periods before its DNA instructs the cell to make new viruses. In most people, HIV will eventually begin to destroy T4 cells. The number of T4 cells in the blood may slowly decline as HIV kills them, both directly, as new viruses bud from the cells, and indirectly.

Although loss of T4 cells is the main defect of the immune system in AIDS, the system may start acting abnormally long before the T4 cells begin to die off. For example, infected T cells cannot interact normally without other immune cells, and they fail to recognize foreign antigens.

HIV seems to be able to infect any cell that has CD4 molecules on its surface. Besides T4 cells, the principal cells that HIV infects are monocytes, which circulate in blood, and macrophages, which are monocytes that have migrated into body organs and taken on specific functions. Monocytes and macrophages engulf and process antigens, eventually shuttling fragments of the antigen back to the surface of the cell. In a normal immune response, the monocytes or macrophages then "present" the foreign antigen to T cells. T4 cells must come into contact with the processed antigen before they can launch an immune response against an invader. Unlike T4 cells, monocytes and macrophages appear to be relatively resistant to killing by HIV. By infecting monocytes, HIV finds a safe haven from immune response that normally limit viral infections, while building up reservoirs of virus to spread around the body.

Major Efforts Focus on Treatment and Vaccine Development

The development of safe and effective new drug treatments for HIV and associated OIs is a major focus of NIH-supported research. The search for new AIDS drugs is essential.

AZT (azidothymidine), also known as zidovudine, is the only drug currently approved for the treatment of HIV infection and AIDS. However, it is not effective in all patients and, even then, may be effective only for a limited time.

A vital concentration of NIH-supported clinical research on HIV takes place in the AIDS Clinical Trials Group (ACTG), a cooperative clinical trials network that includes 47 AIDS Clinical Trials Units (ACTUs). The ACTG investigates and conducts experiments on promising drug therapies, including: dideoxyinosine (ddI), which has been demonstrated to be an anti-HIV agent for patients with AIDS or symptomatic HIV disease known as AIDS-related complex (ARC); interferon alpha (IFN-alpha), which slows virus production and may reduce the risk of developing AIDS-related OIs when administered to asymptomatic HIV-infected persons; and interferon-beta (IFN-beta) which has shown preliminary signs of antiviral activity in AIDS patients with poor prognosis due to Kaposi's sarcoma, a rare cancer. Furthermore, the Food and Drug Administration (FDA) has approved AZT for persons with earlier stages of HIV infection, since recent trials have proved that AZT slows disease progression.

The NIH has launched a significant effort to increase the number of community-based clinics around the country and to expand access to promising AIDS drugs in parallel with clinical trials. The Community Programs for Clinical Research on AIDS (CPCRA) currently serves over 30,000 people. CPCRA was established in 1989 with financial support from the NIAID to expand AIDS clinical research to community-based clinics and to provide primary care for persons with AIDS. In 1990, the CPCRA initiated its first clinical trial, a comparison of therapies for infection with the toxoplasma parasite. In addition, a new system called "Parallel Track" is being developed to provide promising drugs to persons unable to participate in clinical trials.

In addition to the CPCRA and "Parallel Track," the NIH supports and conducts a variety of outreach and educational programs for health professionals, persons with AIDS, and those interested in learning about AIDS. These activities include numerous conferences, workshops and information services, and the AIDS Clinical Trials Information Service (ACTIS), a computerized resource that provides information on NIH- and industry-sponsored clinical trials of new therapies for persons infected with HIV.

Exciting research in the area of vaccine development has sparked hope within the scientific community that a safe and effective vaccine against AIDS may be possible. Encouraging results have come from research conducted on the SIV virus, the primate analogue of HIV found in macaque monkeys; and from adjuvants, compounds that enhance the body's immune response to a vaccine. In addition, two experimental AIDS vaccines are being evaluated in NIH-sponsored phase I studies. Phase I trials evaluate the safety and immunogenicity (ability to provoke an immune response) of the vaccines in a small number of healthy volunteers.

National Institute of Allergy and Infectious Diseases

AIDS is an important focus of the research program of the National Institute of Allergy and Infectious Diseases (NIAID). Research conducted and supported by NIAID has important implications for understanding the mechanisms of HIV infection and for the design of strategies to prevent HIV infection as well as to control virus expression in infected individuals.

Basic Research Is Foundation of Clinical Advances

Several intramural laboratories of the NIAID focus on basic research on the nature of the AIDS virus. One group of scientists, headed by Dr. Anthony S. Fauci, NIAID Director, is studying the mechanisms by which HIV infects different cells of the immune system and how the immune system responds to HIV infection. The precise understanding of these complex processes is leading to the design of rational approaches to antiviral therapy, immune reconstitution, and vaccine development.

Dr. Fauci and colleagues have concentrated on the mechanisms involved in the regulation of HIV expression, particularly on the role of cytokines. Cytokines are powerful chemical messengers secreted by white blood cells that play a major role in the regulation of the normal immune response.

Certain cytokines, like tumor necrosis factor-alpha and -beta (TNF- α and TNF- β), interleukin-6 (IL-6) and granulocyte-macrophage colony-stimulating factor (GM-CSF), can stimulate the production of HIV in T4 cells and other infected immune cells at different stages of maturation. Other cytokines, namely interferon alpha (IFN- α) and transforming growth factor-beta (TGF- β), deter production of the virus by repressing the expression of HIV genes. Dr. Fauci, Dr. Guido Poli, and other NIAID colleagues have also shown that glucocorticoids (a type of steroids) are co-inducers of HIV expression with interleukin-2 (IL-2), GM-CSF, and interferon gamma (IFN- γ). Dr. Gopi Pantalco, Dr. Fauci, and their colleagues have demonstrated that leukocyte-adhesion molecules (one that play a role in the adhesion of T cells to other white cells) are involved in the cell-to-cell spread of HIV and that this spread can be blocked by antibodies to these molecules. They have also shown that the combination of suboptimal concentrations of CD4 (a protein found on the surface of T4 cells) and the monoclonal antibody to CD4 resulted in a synergistic and enduring suppression of HIV replication.

NIAID intramural scientist, Dr. Malcolm Martin, Mr. George Englund, and others have determined that HIV replicates better in CD4⁺ T cells than in monocytes or macrophages. In addition, they found that a single HIV clone produces different envelope protein (the outer coat of the virus), depending on the infected cell type from which it is taken.

Ms. Elizabeth Ross and Dr. Martin have looked at the long terminal repeat (LTR), the switch-like genetic region that is responsible for activating the HIV genes. They have found that the LTR contains multiple elements to which cellular proteins can attach to activate the virus. The presence or absence of different combinations of these elements affects activation.

Drs. Fauci, Lane, Schnittman, and colleagues found that an increased viral burden in patients with asymptomatic HIV infection was directly associated with immunosuppression and rapidly progressive clinical disease. This suggests that determining viral burden before substantial immunosuppression and clinical disease develop could help to identify patients who might benefit from earlier and more aggressive antiviral therapy.

New Drug Development Continues

NIAID sponsors a variety of basic and applied research efforts to develop safe and effective treatments for AIDS-related diseases. NIAID currently funds 34 National Cooperative Drug Discovery Groups (NCDDGs) that foster collaboration among scientists from academia, industry, and Government. Research supported through the NCDDGs fosters rational drug design by analyzing specific viral targets, such as enzymes like reverse transcriptase (RT).

It is important, however, to identify agents that are active against molecular targets other than RT. One such target is HIV protease, an enzyme essential to HIV replication. Interference with the function of HIV protease leads to the production of immature or noninfectious virus particles. Protease inhibitors are being developed in several NCDDGs under the direction of Dr. William Haseltine, Dana-Farber Cancer Institute, Boston; Dr. John Erickson, Abbott Laboratories, Abbott Park, Illinois; and Dr. Garland Marshall, Washington University, St. Louis.

A second target under investigation is HIV Tat, a protein essential for replication of the virus. Dr. Ming-Chu Hsu and colleagues at the Hoffmann-La Roche NCDDG in Nutley, New Jersey, have developed a compound with anti-HIV Tat activity, the first demonstration that drugs targeted specifically to HIV regulatory proteins can be developed.

A promising class of potential anti-HIV drugs includes myristylation inhibitors, which block another stage in the viral life cycle. NCDDG investigator Dr. Jeffrey Gordon of Washington University in St. Louis has developed analogs of myristic acid, a fatty acid critical for viral assembly. One new analog can inhibit HIV in infected cells without producing toxicity.

Recent experiments conducted by NIAID intramural scientists Dr. Bernard Moss, Dr. Edward Berger and their colleagues have shown that a genetically engineered therapeutic agent combining CD4 with a toxin (PE40) from common soil bacteria effectively

kills HIV-infected human cells in culture, without harming noninfected cells. In addition, infectious AIDS virus was eliminated from the test system when AZT was used together with the agent (CD4-PE40). CD4-PE40 was developed in cooperation with Dr. Ira Pastan and his colleagues at the National Cancer Institute.

Vaccine Advances Raise Optimism

A number of exciting developments have been reported in the past year by researchers participating in the 13 NIAID-supported National Cooperative Vaccine Development Groups (NCVDGs).

Independent studies by NIAID-supported researchers Dr. Michael Murphey-Corb of the NCRR-supported Delta Regional Primate Research Center in Covington, Louisiana, Dr. Murray Gardner of the University of California, Davis, and Dr. Gunnar Biberfeld of Sweden's Karolinska Institute in Stockholm have demonstrated that rhesus monkeys can be given long-term protection from viral infection by intravenously administering inactivated whole virus vaccines against SIV. In addition, Drs. Murphey-Corb and Gardner have reported preliminary evidence suggesting that a vaccine based on one strain of SIV can provide protection against another SIV strain. This work provides hope that variations in the virus may not be as significant an obstacle to vaccine development as had been anticipated.

NIAID supports 8 AIDS Cooperative Adjuvant Groups (ACAGs), which are studying compounds that enhance the body's immune response to a vaccine. At present, the only adjuvant approved for human use is alum, an aluminum compound. Because HIV antigens generally produce a weak immune response, it is anticipated that other adjuvants will be required to obtain a comprehensive and effective immune response against HIV. NCVDG investigators Dr. Murphey-Corb, Dr. Gardner, and Dr. Ronald Desrosiers at the NCRR-supported New England Regional Primate Research Center in Southborough, Massachusetts, have used analogs of muramyl dipeptide (MDP) as adjuvants with their successful whole inactivated SIV vaccines, indicating that this type of adjuvant may be effective for use with AIDS vaccine.

A number of advances have been made in studies of immunology related to AIDS vaccine development in the past year. NIAID grantee Dr. Janis Giorgi of the University of California at Los Angeles and her colleagues have shown that certain subsets of T cells, which have receptors for molecules known as CD8 and which are associated with cell-killing activity, disappear as the disease progresses. NIAID-supported investigators Drs. Jay Levy and Chris Walker of the University of California at San Francisco, and Dr. Bruce Walker at Massachusetts General Hospital in Boston, and NIAID intramural scientist Dr. Scott Koenig have found that some CD8 cells may be able to suppress viral replication through mechanisms other than cell killing. These investigators mapped epitopes of several HIV proteins. (An

epitope is that antigenic region of a protein with which the immune system interacts.) These findings provide insight into the critical components of the immune response to HIV and may assist in the development of an effective vaccine against AIDS.

NIAID is evaluating two experimental AIDS vaccines for safety and efficacy in phase I trials at the NIH's Warren Grant Magnuson Clinical Center and at five Institute-sponsored AIDS Vaccine Evaluation Units (AVEUs) located at universities around the country. One trial is evaluating a genetically engineered vaccine containing the HIV envelope protein gp160 that is manufactured by MicroGeneSys, Inc. So far, no medically significant adverse effects have been observed and modest blood and cellular immune responses have been detected, particularly after repeated booster immunizations.

Another phase I trial is testing a recombinant vaccine made by inserting the HIV envelope glycoprotein gp160 into live vaccinia virus (which is used in the smallpox vaccine). Manufactured by Bristol-Myers Squibb, the HIVAC-1e vaccine is being tested in 54 persons who have never been immunized against smallpox.

Animal Models Essential in Drug, Vaccine Research

Animal models are essential for studying the mechanisms of HIV infection and for evaluating new drugs and vaccines.

In a recent study, NIAID and NCRR grantee Dr. Louis Martin and colleagues at the Delta Regional Primate Research Center in Covington, Louisiana, gave AZT to rhesus monkeys after exposure to SIV to determine when the drug should be started to have maximum efficacy. Animals that began receiving AZT at 1 or at 8 hours after exposure had less severe infections and disease and survived longer than those receiving AZT at 24 hours and at 72 hours after exposure. Animals started on AZT at 24 or 72 hours, however, had less severe and less rapidly progressing disease than untreated animals. The information from this study has been useful in the design of an upcoming clinical trial of AZT to prevent perinatal transmission of HIV.

Other studies have been carried out in the experimental SCID (severe combined immunodeficiency) mouse model. After these mice, which lack a functional immune system, are reconstituted with human immune system tissues, they can be used to evaluate responses to therapy. NIAID-supported researcher Dr. Michael McCune of SysTemix, Inc., in Palo Alto, California, has reported that, in SCID mice treated with AZT before they were infected with HIV, no viral replication could be detected. In contrast, all of the mice that did not receive AZT became infected after exposure to HIV. Dr. McCune also found that the drug ddI suppressed the SCID mice.

Animal models may also provide data about immune responses to candidate vaccines. One study with SCID mice is being conducted by NIAID grantee Dr. Donald Mosier of the Medical Biology Institute in La Jolla, California, in collaboration with NIAID-supported AIDS Vaccine Evaluation Units. NIAID has coordinated the acquisition of human immune cells from volunteers vaccinated with HIV recombinant vaccines. The mice reconstituted with these cells have now been challenged with live HIV. Preliminary results suggest that the model will be useful in evaluating the factors that contribute to protective immunity.

Epidemiology Studies Focus on HIV Transmission

The NIAID-supported Multicenter AIDS Cohort Study (MACS) has focused on the natural history and behavioral correlates of disease transmission and progression in more than 5,000 homosexual and bisexual men, most of whom have been followed since 1984. MACS also collects and maintains biological specimens such as blood, urine, and semen from study participants at four sites in the United States: the Johns Hopkins University, the University of California at Los Angeles, Northwestern University, and the University of Pittsburgh. These specimens are being used in current studies of HIV infection and will be available for future studies.

Along with the NIAID-supported San Francisco Men's Health Study (SFMHS), MACS examines the clinical, immunologic, virologic, and neuropsychologic complications of progressive HIV infection and analyzes therapies employed to combat infection.

Both studies have provided a number of important findings during the last year. MACS investigator Dr. John Fahey of the University of California at Los Angeles, in collaboration with other MACS scientists, found that, of eight markers studied, progression to AIDS was predicted most accurately by the level of CD4⁺ T cells in combination with the blood level of either neopterin or β -2-microglobulin (β -2M), two substances that are produced during activation of the immune system by infections or malignancies. SFMHS investigator Dr. Robert Anderson and his colleagues have also studied the use of β -2M levels and CD4⁺ T cell counts to predict the onset of AIDS in HIV-infected people. They concluded that β -2M level predicted the development of AIDS independently of the number of T cells.

Several MACS investigators, including Dr. John Phair of Northwestern University in Chicago and Dr. Alvard Munoz of the Johns Hopkins University in Baltimore, have demonstrated that a drop in CD4⁺ T cells below 200/mm³ in HIV-infected individuals is associated with an increased risk for developing Pneumocystis carinii pneumonia. This discovery contributed to a recommendation by the Public Health Service Task Force (an interagency group that coordinates the Government's AIDS efforts) to use prophylactic drugs (oral trimethoprim with sulfamethoxazole or aerosolized pentamidine) to prevent PCP in

persons with fewer than 200 CD4⁺ T cells or with AIDS-defining clinical signs.

MACS investigators Dr. Justin McArthur at Johns Hopkins University and Dr. David Clifford at Washington University in St. Louis and their colleagues have found no measurable differences in motor function, cognitive orientation, or attention span between asymptomatic HIV-infected persons and high-risk noninfected persons. Although many AIDS patients may suffer dementia and neurologic illness in later stages of the disease, the studies provide additional evidence that asymptomatic people infected with HIV are capable of holding jobs that demand cognitive skills or assuming responsibility for public safety.

NIAID's Community Programs for Clinical Research on AIDS (CPCRA) and the American Foundation for AIDS Research (AmFAR) are cosponsoring an observational database study to systematically compile information on the progression of HIV infection in a broad spectrum of individuals. This will be the largest study of its kind ever conducted, with the potential participation of several hundred primary care physicians and several thousand patients, specifically those from minority populations.

NIAID-supported epidemiologic studies are addressing many of the issues surrounding intravenous drug users, their sexual partners, and their children. Some of these are described in the separate report on pediatric AIDS.

Studies of behaviors associated with the transmission of HIV are closely linked with biological studies in a number of epidemiologic investigations sponsored by NIAID. Recently, NIAID's Ms. Amy Sheon and Dr. Penelope Hitchcock coordinated the development of the Institute's input into a 10-year plan for increasing behavioral research at NIH.

Examples of behavioral research supported by NIAID include the demonstration by the San Francisco Men's Health Study (SFMHS) of dramatic reductions in high-risk sexual practices among homosexual and bisexual men. SFMHS investigator Dr. Thomas Coates and colleagues have found, however, that relapses into unsafe practices are common, particularly among younger men and among men who have not had a close friend or regular sexual partner with AIDS.

Behavioral research is part of other NIAID-supported investigations. NIAID-supported investigator Dr. Donald DesJarlais and colleagues at the State University of New York/Health Science Center in Brooklyn have held focus groups of inner-city women to learn more about how decisions are made about issues of sex, drugs, and reproductive choices. Findings are being used to modify questionnaires and research questions, and to develop more culturally sensitive AIDS risk reduction interventions. Other behavioral research supported by NIAID

includes an evaluation of the effects of counseling interventions designed to reduce high-risk behavior. This evaluation is part of a study conducted by Dr. Mauricio Hernandez of the International Center for AIDS Research at the University of Mexico in Mexico City, in collaboration with Dr. Nancy Mueller of Harvard University.

NIAID grantee Dr. Joan Kreiss studied the efficacy of intravaginal nonoxynol-9 (N-9) spermicidal sponges in reducing or preventing HIV transmission among prostitutes in Nairobi, Kenya. After 2 years of study, Dr. Kreiss and her international collaborators were surprised to find that sponges containing N-9 may actually facilitate HIV transmission. Consequently, this study has been stopped on ethical grounds. It is hypothesized that N-9 may cause disruptions in the normal barrier functions of the vaginal mucosa. However, the sponges may also cause abrasions and ulcers, with consequent high risk for HIV infection.

Clinical Trials are Major Research Emphasis

The primary focus of NIAID-supported clinical research on HIV is the AIDS Clinical Trials Group (ACTG), a nationwide cooperative clinical trials network that includes 47 AIDS Clinical Trials Units (ACTUs), 15 of which are devoted exclusively to pediatric trials.

As of October 22, 1990, nearly 12,000 persons had participated in ACTG studies. Currently, approximately 7,500 participants are being followed in 86 active clinical trials. More than 200 agents have been evaluated for potential entry into ACTG clinical trials.

In March 1990, FDA approved the use of lower doses of AZT to treat AIDS and the early stages of HIV infection. FDA approval was based on two landmark ACTG trials that demonstrated that AZT significantly slows the progression of HIV disease in persons with early AIDS-related complex (ARC) and asymptomatic HIV infection. The studies found that both high-dose (1,200 mg/day) and low-dose (600 mg/day) AZT are effective in delaying disease progression in asymptomatic individuals and that low-dose AZT is at least as effective as the higher dose and is less toxic.

Persons may begin AZT therapy in the early stages of infection and as many as 12 years may elapse between the time of infection with HIV and the development of AIDS; thus, viral resistance to drug therapy is an important consideration for future research. ACTG investigator Dr. Douglas Richman of the University of California, San Diego, and colleagues at Wellcome Research Laboratories reported that AZT-resistant strains of HIV were isolated from some patients with AIDS or ARC who had received the drug for more than 6 months. The investigators also found that virus from healthier patients developed resistance to AZT at slower rates and at lower levels. These findings suggest

that early intervention with low-dose AZT therapy might result in a longer period of effective treatment.

Dr. Fauci, Dr. Lane, and colleagues have conducted several studies of interferon alpha (IFN- α) alone or in combination with AZT in persons with early HIV infection. These studies have shown that IFN- α appears to slow virus production and reduce the risk of developing AIDS-related opportunistic infections when administered to HIV-infected persons who are asymptomatic. Another NIAID intramural study reported by Dr. Richard Davey and colleagues found that GM-CSF given to AIDS patients treated with AZT and IFN- α can alleviate a low amount of white blood cells known as neutropenia, a potential side effect of either agent.

Another agent under widespread investigation is ddI, which is being studied in phase II clinical trials (which assess a drug's efficacy in a few hundred volunteers) in parallel with distribution under an expanded treatment IND (investigational new drug) for patients who are not eligible for enrollment in controlled trials. (IND is a step in the drug approval process accorded by FDA after submission of the data on laboratory and animal studies of the drug. IND status must be obtained before a drug can be tested in humans.) The ACTG is conducting clinical trials in collaboration with the drug's manufacturer, Bristol-Myers Squibb. Phase I trials conducted by ACTG investigators Dr. Raphael Dolin at the University of Rochester in Rochester, New York, and Dr. Fred Valentine at New York University showed that ddI has considerable potential as an anti-HIV therapeutic agent in patients with AIDS or ARC.

Approximately 33 percent of the ACTG's ongoing clinical trials are studying therapies for opportunistic infections related to HIV infection. A multicenter clinical trial, conducted by the ACTG and the NIAID-supported Mycoses Study Group, found that fluconazole, a drug recently approved as an alternative treatment for fungal diseases in persons with AIDS and other immune deficiencies, is at least as effective as, and may be superior to, the standard treatment in preventing recurrences of cryptococcal meningitis. For this life-threatening infection that affects the brain and nervous system, the standard treatment is amphotericin B, a toxic drug that must be administered intravenously. Based on the study, maintenance therapy with amphotericin B now can be replaced by fluconazole, a considerably less toxic drug that can be administered orally. The study was led by Dr. Donald Armstrong of the Memorial Sloan-Kettering Cancer Center, Dr. William Dismukes of the University of Alabama at Birmingham, and Dr. William Powderly of Washington University in St. Louis.

NIAID scientist Dr. Lane and colleagues, along with investigators at the NIH Clinical Center and the National Eye Institute, have reported promising preliminary results from the first controlled randomized clinical trial of a drug to treat CMV (cytomegalovirus) retinitis, a serious, sight-threatening eye

infection that affects many persons with AIDS. The scientists found that the experimental drug foscarnet was effective in delaying progression of the disease. Clinically significant anti-CMV activity was also demonstrated by a decreased ability to culture CMV from the blood and urine of the study participants.

Dr. Lane and colleagues have also found that a combination of trimetrexate and leucovorin resulted in an increased survival among HIV-infected individuals with PCP, many of whom were intolerant to standard therapy or had no other treatment options. Ongoing controlled studies are comparing the effectiveness and safety of trimetrexate and leucovorin with other anti-PCP therapies.

Community Programs Begin Clinical Trials

NIAID supports 18 AIDS community-based treatment research programs in 14 cities across the country. Established in 1989, these Community Programs for Clinical Research on AIDS (CPCRA) have expanded AIDS clinical research to include community-based clinics, where many persons with AIDS receive primary care.

The first CPCRA study compares the effectiveness of two drugs to prevent recurrence of toxoplasmic encephalitis, a life-threatening parasitic infection of the central nervous system, in persons infected with HIV. The two widely available drugs, clindamycin and pyrimethamine, have been used to treat patients with acute toxoplasmic encephalitis.

Outreach Programs Target Health Professionals

NIAID conducts a variety of outreach and educational programs for health professionals, persons with AIDS, and those interested in learning about AIDS and its treatment. The Institute sponsors and participates in numerous conferences and workshops for scientists, physicians, nurses, and social workers on AIDS-related topics. Special efforts have been made this year to reach health professionals working with minority populations. Workshops have been sponsored in cooperation with the National Medical Association and the Health Resources and Services Administration.

In March 1990, NIAID sponsored a 2-day conference on state-of-the-art AZT Therapy for Early HIV Infection. A summary of the conference and an audiotape of conference highlights were mailed to more than 60,000 physicians. Videotapes of conference highlights in English and Spanish have also been prepared. The full document was published in the American Journal of Medicine.

NIAID sponsors the AIDS Clinical Trials Information Service (ACTIS) in cooperation with CDC and FDA. ACTIS is a computerized central resource that provides information on NIH- and industry-sponsored clinical trials of new therapies for persons infected with HIV. The service, which can be reached through a toll-free

number (1-800-TRIALS-A), receives approximately 2,000 calls per month.

The Institute's Office of Communications distributes a variety of materials that describe the latest accomplishments of the NIAID AIDS effort. NIAID has recently produced brochures and accompanying audiotapes, in English and Spanish, for physicians and patients about clinical trials and AIDS. Eight ACTUs conduct outreach programs for AIDS education and technology transfer in addition to their clinical trial and basic research activities.

National Cancer Institute

The National Cancer Institute (NCI) conducts research on the basic biology, including molecular biology and mechanisms of infection; studies the pathogenesis, transmission, and immunology of HIV infection; develops drugs, vaccines, and biological therapies to prevent and treat AIDS; and analyzes patterns of occurrence of HIV infection and disease.

HIV Tat Protein Stimulates Kaposi's Sarcoma Cell Growth

Kaposi's sarcoma (KS) is frequently associated with HIV infection. Previously, Dr. Robert Gallo's group at NCI and other scientists have shown that growth factors play a key role in the development of this tumor. Also, when other researchers introduced an HIV-1 regulatory gene known as tat into the germ line of mice, the mice developed skin lesions closely resembling those of KS.

Now, NCI scientists Drs. Barbara Ensoli, Giovanni Barillari, and Gallo, with S. Zaki Salahuddin of the University of Southern California, and Dr. Flossie Wong-Staal of the University of California, San Diego, have demonstrated that the protein, Tat, produced by the tat gene of HIV-1, specifically promotes growth of AIDS-KS cells.

The NCI scientists added fluid in which HIV-1-infected cells had been grown to cultured cells derived from KS lesions of AIDS patients. The fluid promoted growth of the KS cells, but this proliferation was specifically inhibited by anti-Tat antibodies, indicating that the growth stimulation had occurred in response to Tat present in the fluid. Presence of Tat in the fluid was also demonstrated directly and found to correlate in time with the optimal growth-promoting effect.

These findings suggest that a viral regulatory gene such as tat can function by producing a biologically active protein that acts directly as a growth stimulator, possibly leading to tumor formation. The data further indicate that tat may be involved in the development and progression of KS in HIV-1-infected individuals, and imply possible approaches to interfering with these processes.

Novel Approaches Used in Drug Development

The NCI is continuing to screen synthetic compounds and natural product extracts for anti-HIV activity at the rate of about 20,000 materials annually. Six substances are currently under preclinical development leading toward clinical trials, and an additional 40 to 50 active crude materials are being subjected to chemical purification.

NCI recognizes that many complex molecules found in nature are beyond the synthetic capabilities of scientists. These

compounds, referred to as natural products, often have unique structures and mechanisms of action. The institute's natural products program, under the direction of Dr. Gordon Cragg, has already accumulated 9,500 pure compounds from a diverse variety of plant and animal life, including products from tropical rainforests, marine organisms, bacteria, and fungi. One natural product purified from a bacteria, called a sulfolipid, has shown promising activity in the AIDS screen, and further studies to identify potential analog of this compound are under way.

Another active compound identified in the screen, prostratin, is of great interest because it belongs to an entirely new class of compounds with anti-HIV activity. Prostratin activates an enzyme--protein kinase C--known to be important in cellular communication pathways.

NCI investigator Dr. Donald Blair and colleagues have also found that a plant-derived chemical known as camptothecin strongly inhibits the proliferation of HIV-1 in the test tube. Camptothecin was originally developed by NCI as an antitumor agent and has activity against a wide variety of animal tumors. Both its antitumor and anti-HIV effects are thought to derive from its ability to inhibit an enzyme--topoisomerase I--necessary for RNA and DNA synthesis. The results obtained thus far with camptothecin are exciting, because this compound, too, may represent a new class of drugs with antiretroviral potential.

The supercomputer in Dr. Jacob Maizel's Laboratory of Mathematical Biology at NCI's Frederick Cancer Research and Development Center (FCRDC) continues to play an important role in expanding our knowledge of the molecular structure of the HIV genome. Predictions of the structure of a regulatory region of the genome (Rev responsive element) made using the supercomputer have been confirmed by experimental studies in several laboratories. Collaborative research efforts are beginning to reveal the function of this regulatory element, which is essential to viral growth, as scientists design modified elements with the supercomputer and then test their functionality by experiment. These studies should make it possible to design specific antiviral agents.

In other studies, Dr. Alexander Wlodawer's group at Advanced BioScience Laboratories, Inc.-Basic Research Program (ABL-BRP), FCRDC, under contract to NCI, rapidly analyzed the X-ray crystallographic structure of a critical enzyme, HIV protease, with the help of the supercomputer. Dr. Wlodawer and his colleagues have also been able to analyze the crystal structure of the enzyme combined with a synthetic inhibitor.

AIDS Drugs Tested in Clinical Trials

In 1990, NCI scientists evaluated the long-term activity and toxicity of a potent inhibitor of HIV replication in the test

tube. Drs. Robert Yarchoan, James Pluda, Hiroaki Mitsuya, Neil Hartman, Samuel Broder and colleagues administered ddI to 37 adults with AIDS or ARC on an escalating-dose schedule. In addition, the researchers gave ddI to 21 other patients, many of whom had previously been treated with AZT, or with ddA (dideoxyadenosine), an experimental AIDS drug related to ddI.

The investigators found that doses of ddI of 9.6 mg/kg per day or below were well tolerated for up to 21 months. In contrast, doses above 9.6 mg/kg per day were frequently associated with toxicities such as pain in the feet and inflammation of the pancreas and liver. The investigators have therefore recommended that doses above 9.6 mg/kg per day not be used.

A group of patients receiving 3.2 to 9.6 mg/kg per day of ddI had long-term immunological improvement and reduced levels of serum HIV p24 antigen. Immunologic changes were especially seen in patients who had little previous AZT therapy. Also, five patients with HIV-induced mental dysfunction improved with ddI.

The researchers conclude that ddI might be useful for long-term therapy of AIDS, and that further studies of the agent are warranted. As a result of this and other studies, ddI is being made available on a compassionate basis to over 11,000 patients with AIDS or AIDS-related complex while large controlled trials are being conducted.

New Approaches to AIDS Vaccines

NCI scientists Drs. Prem Sarin and Gallo, along with Dr. Alan Goldstein of The George Washington University Medical Center, Washington, D.C., Drs. Daniel Zagury and Ammar Achour at the Universite Pierre et Marie Curie, Paris, France, and colleagues, have reported encouraging results from the first human trials of an HGP-30 AIDS vaccine. The study was conducted at the Kobler AIDS Clinic at St. Stephen's Hospital in London.

HGP-30 is a synthetic peptide (protein fragment) related to p17, a protein from the core of HIV-1. Previous studies have shown that HGP-30 elicits an immune response in several kinds of animals. Also, antibodies directed against HGP-30 neutralize HIV-1 in laboratory cultures, suggesting that the peptide could be useful in an AIDS vaccine.

Studying the immune response to HGP-30 in healthy and HIV-infected volunteers, the investigators found that the peptide induces production of HIV-specific CD8+ killer T cells, which can destroy all types of HIV-infected cells. Recent clinical studies have shown that the presence of strong CD8+ T-cell killing and antiviral activity in HIV-infected patients is correlated with the patients' long-term survival.

The researchers will be conducting expanded clinical trials of an HGP-30 vaccine at the University of Southern California

Medical Center and at San Francisco General Hospital.

Whole virus vaccines, however, offer certain advantages over subunit vaccines. Because they contain many antigens (substances that provoke an immune response), rather than just one or two, they are more likely to protect recipients against several different strains of the rapidly mutating AIDS virus.

Contractors at NCI's FCRDC have now developed noninfectious variants of HIV-1 that hold promise both as potential AIDS vaccine strains and as nonhazardous surrogates for infectious HIV-1 in research laboratories. Drs. Robert Gorelick and Alan Rein of ABL-BRP, and Dr. Larry Arthur and colleagues of Program Resources, Inc., isolated HIV-1 mutants that have alterations in a sequence of the gag gene that is found in all retroviruses. The fact that this sequence has persisted throughout the evolution of retroviruses suggests that it plays an essential role in the viruses' life cycles. The viral particles produced by the mutants were not only greatly deficient in RNA, the scientists found, but also noninfectious.

FCRDC's AIDS Vaccine Program is now trying to produce sufficient quantities of noninfectious mutant HIV-1 for further experiments. Ultimately, the mutant virus could possibly be used in human vaccine trials.

AIDS Surveillance Indicates HIV Treatment is Effective

Since mid-1987, fewer AIDS cases than expected have been reported among homosexual and bisexual men in the United States. This improvement in AIDS incidence was most notable in New York City, San Francisco, and Los Angeles, but was striking among all homosexual and bisexual men in the United States. In contrast, the incidence of AIDS among intravenous drug users continued to climb.

NCI epidemiologists Drs. Mitchell Gail, Philip Rosenberg, and James Goedert have now used three independent sources of data--placebo-controlled trials, pharmaceutical company reports, and the San Francisco Men's Health Study--to demonstrate that most of the observed reduction in AIDS incidence can be traced to giving AZT prophylactically to seriously immunodepressed HIV-infected individuals, a practice begun in March 1987. Other advances in the medical care of HIV-infected patients, such as use of aerosolized pentamidine, may also have contributed to the change.

In the last 6 months of 1987, there were 13.1 percent fewer AIDS cases among homosexual and bisexual men than expected, while in the first half and last half of 1988 the improvements were 19.6 percent and 29.3 percent, respectively. In New York City, San Francisco, and Los Angeles the reductions were 17.8 percent, 23.2 percent, and 35.9 percent for the respective periods in question.

Risk of Lymphoma and KS Increases in Homosexual Men

Patients with severe symptomatic HIV infection who survive for up to 3 years on antiretroviral therapy may have a relatively high probability of developing non-Hodgkin's lymphoma (NHL), an NCI-led group reports.

It has already been observed that the incidence of NHL has increased in men aged 20 to 49 since 1981; this increase is largely due to HIV-associated lymphomas. In addition, the incidence of NHL is increasing in other segments of the population for unknown reasons: between 1973 and 1987, the overall incidence increased by more than 50 percent. Although lymphomas associated with AIDS now account for only a small percentage of the increase, and because they are occurring in a group that can be carefully observed, they may offer special opportunities for increased understanding as well as early intervention.

Drs. James Pluda, Robert Yarchoan, Samuel Broder, and colleagues at NCI, along with scientists at NINDS, the CC and Georgetown University, Washington, D.C., found NHL developed in eight of 55 patients entered in trials in NCI's Clinical Oncology Program from 1985 to 1987. These patients, all of whom had AIDS or severe AIDS-related complex, had received AZT, either alone or combined with other drugs. The patients who developed NHL had displayed severe T4-cell depletion for a median of more than 15 months before the lymphoma was diagnosed.

The researchers suggest that profound immunosuppression with substantial T4-cell depletion may in itself be an important factor in the development of these lymphomas. Patients receiving AZT alone or along with other drugs may be more likely than others to develop NHL simply because they survive longer. In addition, the lymphomas observed in this study were the same type as those that characteristically develop in patients with untreated HIV infection, making it less likely that AZT was a direct cause of these tumors.

However, the investigators do not completely discount the possibility that antiretroviral therapy may have played a direct role in causing the lymphomas. They indicate that it will be important to sort out the relative contributions of immunosuppression, prolonged survival, antiretroviral therapy, and perhaps other unrecognized factors in the development of NHL in these patients, in order to learn how to minimize the occurrence of the illness.

NCI epidemiologists Drs. Charles Rabkin, and James Goedert, and colleagues have also reported that among HIV-infected homosexual men who have been evaluated annually, both NHL and KS continue to pose a high risk. In contrast to national AIDS surveillance data, which have shown a relative decrease in KS as an initial AIDS diagnosis, the investigators demonstrated that

the annual risk of KS did not decline, with approximately 21 percent of men infected with HIV for ten years having this malignancy. About 18 percent developed NHL after 10 years of HIV infection, and the risk of NHL increased markedly during the latter years, coincident with severe HIV-induced immunodeficiency.

These studies suggest that substantial increases in the incidence of AIDS-related NHL and KS may be expected as survival of HIV-infected individuals improves.

National Heart, Lung, And Blood Institute

The National Heart, Lung, and Blood Institute (NHLBI) supports AIDS research as it relates to the safety of the blood supply and to complications of HIV infection involving the heart, lung, or blood.

Variety Marks Approaches to Blood Supply Testing

While pretransfusion testing for HIV-1 has been very effective in increasing the safety of the blood supply, a number of cases of HIV infection have been reported in individuals who received blood that tested negative for the virus. Recently, the appearance of related retroviruses (HTLV-I/II which are associated with T-cell leukemia and HIV-2) that are capable of being transmitted by transfusion has raised new concerns. Blood banks do not currently test for HIV-2, and HIV-2 infection is detected only 60 to 80 percent of the time by tests used to detect HIV-1. Although blood banks now test blood for HTLV, the natural history of the infection with the virus and the mode of infection are not well understood. The NHLBI supports research on the natural history of transfusion-associated retrovirus infection, the modes of infection, and the development of new, more sensitive tests to identify infected blood components, diagnose disease and monitor the effects of therapy.

Dr. Bernard Poiesz, an NHLBI contractor at the University of New York at Syracuse, attempted to determine whether HTLV-I was capable of causing immunosuppression in infected individuals. Only 15 percent of HTLV-I infected individuals demonstrated an immune response to a foreign protein, compared to 46 percent of noninfected persons. Therefore, it appears that infection with HTLV-I does cause a subclinical immunosuppression.

Robert Singer, an NHLBI contractor at the University of Massachusetts in Worcester, developed a simplified, rapid test for assessing the amount of HIV-1 circulating in the bloodstream. This test utilizes the flow cytometer (an instrument that cuts cells) and fluorescent antibody to identify HIV-infected lymphocytes. The number of infected lymphocytes detected by this procedure corresponded to clinical infection, as measured by the number of days that HIV-1 could be cultured from the individual's blood, and was inversely related to the patient's number of CD4 + T cells. This test may provide a useful tool in evaluating response to antiretroviral therapy.

Dr. Myron Essex, an NHLBI and NCI grantee at Harvard University, monitored the blood supply for infection with HIV-2 by studying individuals whose blood also tested positive for HIV-1. (Blood infected with HIV-2 tests positive for HIV-1 60 to 80 percent of the time.) The 913 blood samples used in the study were obtained from 242,000 donors over a three-year period. Using these tests that were specific for HIV-2, Dr. Essex determined that some of the samples were HIV-2 positive.

Photoactive Dye Combined with UV Radiation Inactivates Virus

The use of photoactive compounds to eradicate infectious agents from blood and blood products is gaining impetus and probably will have practical application within a few years. Dr. James Mathews, an NHLBI grantee at Baylor Medical School, Houston, Texas, studied a promising photoactive dye, hematoporphyrin. When activated by certain wavelengths of light, this dye has been shown to inactivate various infectious agents, including SIV. Preliminary results from studies of rhesus monkey blood indicate that hematoporphyrin inactivates a large number of virus particles per milliliter of blood without any deleterious effects to the red blood cells.

Blood Disease Found Related to HIV Infection

Hematologic abnormalities are commonly observed in patients with AIDS, but the factors that cause these changes are not completely understood. These abnormalities include low numbers of white cells, red cells, and platelets, along with changes in the bone marrow where these cells are produced. An NHLBI grantee, Dr. Jerome Groopman, and his colleagues at Harvard University studied the growth of white cell and red cell progenitor cells, the immature cells that give rise to white cells and red cells in AIDS patients and normal uninfected persons. They found no differences in the growth of cells from infected or uninfected bone marrow. HIV or HIV protein neither inhibited cellular growth nor had any effect on the production of blood cell growth factors and regulatory hormones. Although no HIV-DNA could be detected in the red and white cell progenitors, the supporting cells of the bone marrow (stromal cells), as well as the cells giving rise to platelets, were themselves susceptible to HIV infection and were capable of transmitting it to susceptible cells, such as mature cells. The stromal cells and the platelet precursors thus may constitute a reservoir for HIV.

Dr. Neil Young, an NHLBI intramural scientist, used immunoglobulin preparations to treat five AIDS patients with severe anemia due to bone marrow failure (pure red cell aplasia thought to be due to parvovirus infection). All patients responded with a dramatic decrease in circulating parvovirus, an increase in young red blood cells (reticulocytosis), and normalization of the hemoglobin.

NHLBI Studies Pulmonary Complications of HIV Infection

HIV-associated lung disease continues to be a leading cause of death in persons with AIDS. More than 80 percent of individuals with AIDS will develop PCP sometime during their lifetime and most will die of respiratory failure. Other pathogens also infect the lung and cause significant morbidity and mortality. The NHLBI supports research on the pulmonary complications of HIV infection.

Dr. Richard Grumet, an NHLBI grantee at Stanford University, studied the ability of epithelial (surface) and mesenchymal (connective tissue) cells derived from the lung to become infected with HIV-1. He determined that both epithelial and mesenchymal cells derived from the lung could become infected by HIV, and both utilized the CD4 molecule as the viral receptor.

Dr. Richard Rose, an NHLBI grantee at the New England Deaconess Hospital, Boston, Massachusetts, has studied the nature of pulmonary macrophage infection with HIV. Using very sensitive tests that detect the DNA of HIV, Dr. Rose demonstrated that pulmonary macrophages are commonly infected in patients with HIV infection. Although active replication of the HIV-1 did not occur within these macrophages, the cells were capable of transmitting the viral infection to lymphocytes from the peripheral blood.

NHLBI intramural scientist Dr. Ronald Crystal has found that pulmonary macrophages from HIV-seropositive, asymptomatic subjects spontaneously release more superoxide anion (a substance generated by white cells when they are activated) than those from normal subjects. These and related observations are consistent with the concept that the asymptomatic HIV-seropositive state is associated with activation of the immune system despite the absence of any clinical findings.

Dr. Crystal has also found reduced levels of glutathione (a substance that enhances normal immune functioning) in the plasma and lung fluids of HIV-seropositive individuals. This deficiency, too, may play a role in the progressive immune dysfunction of HIV infection. Clinical studies have shown that pulmonary deficiency of functional glutathione can be safely reversed by aerosol administration of it. This treatment may help to reduce the risk of opportunistic pulmonary infections in the HIV-infected population.

Dr. David Baltimore, a colleague of Dr. Rose, then at the Massachusetts Institute of Technology (MIT), examined the molecular basis for the very low levels of HIV-1 expression in alveolar macrophages and found that it was due to suppressed expression of one of the HIV-regulatory genes, which is needed for normal protein synthesis. This observation suggests that agents capable of inhibiting the function of this gene may be useful as therapy.

Dr. Scott Hammer, another of Dr. Rose's colleagues at the New England Deaconess Hospital, demonstrated that the drug verapamil, commonly used in patients with hypertension or heart disease, delays the replication of HIV-1 in mononuclear cells. This effect was achieved through pathways other than alterations in cell surface receptors such as CD4, and, the drug is being further investigated for its potential therapeutic value.

Pulmonary Abnormalities Accompany Asymptomatic HIV-Infection

Baseline data are emerging for 1,486 individuals participating in a study of the natural history of lung complications of HIV-1 infection. Intravenous drug users infected with HIV have about 40 percent more respiratory problems than HIV-infected homosexual men. However, they are also about twice as likely to be smokers. Pulmonary function studies show that single breath-diffusing capacity and forced vital capacity are significantly lower for drug users than for homosexual men. In addition, the pulmonary function of HIV-positive symptomatic subjects was significantly worse than that of HIV-positive individuals who were symptom-free, or of HIV-negative controls. These data suggest that diffusing capacity is reduced in individuals who have advanced HIV infection but do not yet have AIDS.

Cardiac Abnormalities Found in HIV-1 Infected Persons

Dr. Ahvie Herskowitz, a grantee from the Johns Hopkins University, Baltimore, Maryland, demonstrated that cardiac complications of HIV infection occur more frequently in Black and Hispanic individuals than in White homosexual populations. This increased frequency was independent of drug use, although cardiac effects of drug abuse could be detected in some HIV-infected patients. Two NHLBI grantees, Dr. Alan Ross at George Washington University, and Dr. Jiang Gu at Deborah Heart Institute, Browns Mills, New Jersey, were able to demonstrate HIV-1 sequences in individual myocardial (heart muscle) cells that were dissected free of surrounding blood vessels. Dr. Azorides Morales at the University in Florida, demonstrated heart changes in patients with AIDS similar to those found in rheumatic fever. The significance of this finding is being investigated.

New Molecule Blocks HIV-1 Infection

Soluble CD4, a free-floating version of the CD4 molecule, is capable of preventing the infection of T4 cells with the virus by competitively binding to the HIV. However, soluble CD4 is rapidly cleared from the circulation when administered to humans. Dr. Groopman and his colleagues at Harvard University have developed a product that consists of the CD4 molecule fused to an immunoglobulin molecule. The final product will bind viral protein and will block infection of the T cells by HIV, as does the soluble CD4. However, the CD4 conjugated with immunoglobulin (CD4-IgG) has the advantage of remaining at a high concentration in the blood for a relatively long time and, like other immunoglobulins, will bind to white cell. The new CD4 molecule can also increase the destruction of HIV-1 infected cells.

National Institute of Dental Research

The National Institute of Dental Research (NIDR) supports and conducts basic studies of HIV and inhibitory factors in saliva, characterizing early oral signs of AIDS in clinical studies, and designing and implementing epidemiological studies all with the aim of improving treatment and preventing the varied oral complications associated with HIV infection.

Investigators Track an HIV Inhibitory Factor in Saliva

Dr. William Rice, an NIDR grantee, and colleagues at Emory University, Atlanta, Georgia, are characterizing HIV inhibitory substances found in human saliva. The research team has focused on secretory leukocyte protease inhibitor (SLPI), which inhibits enzymes that break down proteins. SLPI is believed to be part of a system of natural mucosal immunity found in normal salivary, nasal, and bronchial secretions. SLPI produced by recombinant DNA technology was found in culture to inhibit both HIV and SIV. SLPI blocks a critical step that occurs before HIV enters a cell to infect it. If similar inhibition can be demonstrated in animals or humans, researchers would be able to devise ways to protect the integrity of T cells. This type of therapy would benefit patients who have already tested positive for HIV.

Patches Developed to Combat Oral Infections in AIDS Patients

Oral candidiasis, a yeast infection and the most frequent opportunistic infection in AIDS patients, ranges from a mild nuisance to a highly debilitating condition. Dr. John Hefferren, supported by an NIDR contract at the University of Kansas in Lawrence, is developing a sustained-release bioadhesive system for preventing and treating this infection. In laboratory studies, he and his colleagues formulated prototype bioadhesive patches designed to be placed in the mouth to release two antifungal drugs, chlorhexidine and nystatin, toward the mucosal surface under the patch or directly into the oral fluid. Preliminary studies show that the patches release these drugs for up to 16 hours and inhibit the growth of the infectious organism, *Candida albicans*. The investigators will next be testing the attributes, safety, and effectiveness of the patches in animals.

Hairy Leukoplakia is a Predictor for AIDS

Dr. John Greenspan, an NIDR grantee at the University of California, San Francisco, investigated the probability of developing full-blown AIDS over time in a group of 143 HIV-positive homosexual/bisexual male patients who did not have AIDS but did have hairy leukoplakia, an oral lesion associated with AIDS. Dr. Greenspan found that 48 percent of the patients developed AIDS within 16 months and 83 percent within 31 months. This very high rate of AIDS development confirms that hairy leukoplakia is an important and reliable predictor of the eventual development of frank AIDS.

Another Key Study Detects HIV in Saliva

In the NIDR intramural laboratories, Dr. Yasuhiro Goto and his colleagues used new DNA technology to detect HIV-1 proviral DNA sequences in saliva of 10 of 20 patients who tested positive for HIV-1. Proviral sequences also were detected in saliva samples collected from six additional patients at four different times. These findings indicate that, under ordinary circumstances, HIV-infected cells are present in saliva in low numbers, arguing for the avoidance of prolonged and intimate contact with saliva.

Insights Gained on Immunosuppression in AIDS Patients

Dr. Sharon Wahl and her colleagues in the NIDR intramural laboratories investigated surface changes of HIV-infected monocytes. One of these changes is the appearance of a newly expressed receptor, FcgammaRIII, on the surface of circulating monocytes. Patients with AIDS show a threefold increase in monocytes with this receptor as compared to individuals without AIDS. This increase may result from elevated levels of a normally occurring cellular hormone, transforming growth factor-beta, which is also believed to contribute to profound immunosuppression in AIDS. These observations provide new insight into the development of this disease and suggest novel approaches for treatment, such as selectively targeting FcgammaRIII for anti-HIV therapies.

National Institute of Diabetes and Digestive
and Kidney Diseases

Much of AIDS research funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) concentrates on deciphering the basic mechanisms of this devastating viral disease; clinical investigations are also an important focus.

Persistence of HIV in Gastrointestinal Tract Studied

NIDDK grantee Dr. Mary Moyer at the University of Texas Health Science Center at San Antonio and her colleagues have found that gastrointestinal epithelial (surface) cells may act as targets for HIV, thus becoming reservoirs for the virus within the gastrointestinal tract. Dr. Moyer undertook her investigation following reports that human colorectal cell lines were susceptible to HIV infection. Her results offer insight into AIDS enteropathy, the chronic diarrhea that besets many AIDS patients.

Early Dietary Intervention May Stem Wasting Syndrome of AIDS

NIDDK grantee Dr. Rowan T. Chlebowski of the University of California Los Angeles Medical Center has found evidence that a high-protein, low-carbohydrate diet supplemented with vitamins might delay the severe, unrelenting weight loss that frequently accompanies AIDS. Dr. Chlebowski compared the caloric intake and nutritional status of AIDS patients to that of healthy, HIV-positive individuals. He found that while AIDS patients' caloric intake was comparatively higher, their nutritional status was worse than that of healthy, HIV-positive individuals. Given the strong relationship between nutritional status and immunologic function, Dr. Chlebowski's findings suggest that dietary intervention should be considered early in the disease course.

National Institute of Neurological Disorders and Stroke

Clinical surveys have detected neurological complications in about 40 percent of adult AIDS patients. Postmortem studies, however, put that figure as high as 80 percent. Neurological damage may be caused directly by the HIV virus or result from a secondary opportunistic infectious agent, and can affect the central or the peripheral nervous system. Occasionally, and often in the earliest phases of HIV infection, nervous system damage is AIDS' only symptom. The National Institute of Neurological Disorders and Stroke Conducts and supports research on the neurological complications of AIDS.

Clues about the damage of the nervous system by interaction of the AIDS virus and immune molecules such as tumor necrosis factor (TNF) come from research by NINDS grantees Drs. Jean E. Merrill and Irvin S. Y. Chen at the University of California at the Los Angeles School of Medicine. They have shown that when the AIDS virus binds to immune cells called mononuclear phagocytes, it triggers production of TNF and another immune molecule, interleukin-1 (IL-1). TNF, which may normally fight brain tumors, can also damage brain blood vessels and myelin. (a substance that coats and insulates nerves) As a result, TNF and IL-1 produced in response to HIV-1 may underlie some features of AIDS, including fever, damage of the brain's blood vessels in AIDS patients with brain tumors, and sensory and motor dysfunction.

AIDS Target Immune Cells in the Brain Found

Research by NINDS intramural scientist Dr. Monique Dubois-Dalcq and her colleagues has implicated another type of immune cell in neurological AIDS. Dr. Dubois-Dalcq recently developed a system to culture human nerve cells derived from the adult brain. She then demonstrated that the AIDS virus can infect and replicate in microglial cells--a type of immune cell that resides in the brain--often leading to cell fusion and death. Because microglial cells help protect the brain from infection, their death may be a key factor in the development of AIDS dementia. Building on this work, Dr. Dubois-Dalcq has also identified the door through which the AIDS virus invades microglial cells--the CD4 receptor. This finding suggests that therapies aimed at blocking the CD4 receptor may inhibit the AIDS virus from spreading in the brain.

AZT Can Damage Muscles

NINDS intramural scientist Dr. Marinos Dalakas has linked long-term AZT treatment to myopathy, muscle damage characterized by weakness, muscle wasting and pain. In 14 of 15 patients with AZT-related myopathy, the condition responded to treatment with anti-inflammatory drugs or discontinuation of AZT. Based on these findings, Dr. Dalakas has suggested new guidelines for

physicians treating those AIDS patients who develop myopathy while on AZT.

Improved Diagnosis of Neurological AIDS with MRI

Although computed tomography (CT) has been the main diagnostic tool for neurological AIDS, recent research by NINDS grantee Dr. Mark Rosenblum and his colleagues at the University of California, San Francisco, suggests that magnetic resonance imaging (MRI) is more appropriate. In their study, MRI was as good as or better than CT in detecting brain abnormalities in 49 of 50 AIDS patients with neurological symptoms. Furthermore, the MRI results significantly influenced diagnosis and treatment in 40 percent of those patients.

Clinical Trial to Assess AZT in AIDS Dementia

NINDS intramural scientist Dr. Dalakas has designed a double-blind trial to compare the effectiveness of low- and high-dose AZT in patients with AIDS dementia. A total of 124 patients will be randomly assigned to a treatment group and followed for 1 year to detect complications and to determine the treatments' effectiveness. Results from this study should reveal if the low dose of AZT recently recommended as safer and equally effective by FDA is sufficient to cross into the brain and prevent or ameliorate AIDS dementia.

National Institute of General Medical Sciences

The National Institute of General Medical Sciences (NIGMS) program of AIDS-related research focuses on efforts to design drugs for the treatment of AIDS based on knowledge about the three-dimensional structures of various proteins involved in the disease. This approach relies heavily on structural biology, a field that studies the relationship between the form and function of biological materials. The techniques of structural biology, which include x-ray crystallography and theoretical chemistry directed toward molecular modeling, have many applications to the study of viruses, including HIV.

Scientists Identify Drug that Blocks AIDS Protein

NIGMS grantee Dr. Irwin Kuntz, Jr. and colleagues at the University of California, San Francisco have recently developed a promising new technique that uses a computer program called "DOCK" TO identify compounds that may help treat AIDS. The approach, which emphasizes molecular shape over chemistry, is a major step forward in the application of basic research to disease-targeted strategies.

Using this technique, the researchers found that haloperidol, a common antipsychotic drug sold as Haldol, blocks the action of a protein essential for the replication of HIV. Unfortunately, haloperidol is not effective against HIV unless the drug is used in doses that greatly exceed the lethal limit for human beings. For this reason, haloperidol is only a starting point for Dr. Kuntz; his team is now making changes in haloperidol's structure that they hope will preserve the desired activity while lessening toxicity. Already, they are investigating some altered compounds that are more effective than haloperidol.

Using "DOCK," Dr. Kuntz and his colleagues examined the structure of a key HIV protein known as a protease. If the action of the protease is blocked, the virus cannot replicate, and its infectious activity stops. The UCSF team first used DOCK to define the shape of the protease grooves usually the site of the molecule's chemical activity. Then they searched for compounds with that shape by using the Cambridge Crystallographic Database, a British database containing the structures of about 60,000 molecules. When the database identified haloperidol as a possible "fit" for the protease groove, the researchers were especially pleased because the drug is readily available and much is already known about it. Because of this, progress toward making an improved haloperidol derivative is occurring relatively rapidly.

National Institute of Child Health and Human Development

AIDS has become one of the leading causes of death in some groups of women and in children and young people in the United States. The National Institute of Child Health and Human Development (NICHD) has focused its AIDS research on investigating the unique features of HIV infection and AIDS in women, infants, children, and adolescents.

Research on Barrier Contraceptives to Help Prevent the Spread of HIV

NICHD is supporting research to develop methods to help prevent the spread of HIV infection. Recognizing that condoms are effective in preventing the heterosexual spread of HIV, NICHD has embarked on an extensive research effort to develop a superior alternative to the latex condom. Support is being provided to several research organizations to develop condoms from polyurethane which should make these devices more resistant to breakage and tearing and thus prevent accidental spread of the virus.

The Institute is also supporting research which attempts to evaluate the potential of spermicidal formulations to prevent the sexual transmission of HIV. This research by Chris Miller at the NCRR-supported California Primate Research Center in Davis involves the search for new spermicidal/virucidal agents, as well as the use of animal models in the study of sexual transmission of the infection. *Cynomolgus* monkeys can be infected by placing SIV in the monkey's vagina. When a spermicidal gel or foam containing nonoxynol-9 is introduced in the animal's vagina prior to the placement of virus, a 50 percent reduction in the rate of infection is observed. Since intensive use of spermicides can result in the irritation of the vaginal wall (mucosa), studies are underway to determine whether such irritation predisposes the animals to subsequent infection.

These animal models allow for the conduct of studies which cannot be done in the human female since it would be unethical to deliberately expose individuals to HIV. These experiments may with time lead to the development of strategies that can limit the sexual transmission of HIV.

National Eye Institute

About 50 percent of the adult population is infected with cytomegalovirus (CMV), but most people carry the virus without harmful effects. However, if the immune system is suppressed, the virus may be activated and affect different parts of the body, including the retina. CMV retinitis threatens the sight of about 20 percent of AIDS patients. Based on projections for increased incidence of AIDS, there may be 20,000 new cases of CMV retinitis in 1992.

If not treated, CMV retinitis progressively destroys the retina. Studies have shown that two drugs, ganciclovir and foscarnet, are effective against CMV retinitis. Ganciclovir is the only drug approved by the FDA for the treatment of CMV retinitis. Because the drug tends to lower the production of bacteria-fighting white blood cells, it must be used cautiously in persons receiving AZT, which produces a similar type of toxicity. The investigational drug, foscarnet, has other side effects but does not suppress white blood cell production and so may be taken concurrently with AZT. NEI is funding the CMV Retinitis Trial to compare the relative safety and effectiveness of the two drugs and to compare the results of immediate and deferred treatment for early-stage CMV retinitis. The study will also evaluate whether either drug prolongs patient survival.

In the study, advanced-stage CMV retinitis patients are randomly assigned to receive immediate treatment with either ganciclovir or foscarnet. In patients whose CMV retinitis is at an early stage--confined to less than 25 percent of the peripheral retina--drug treatment may be either given immediately or delayed unless the disease progresses to the advanced stage. Because it is not known which option is better, study patients with early-stage infection may choose to have either immediate or delayed treatment or to accept random assignment to either group.

The multicenter CMV Retinitis Trial is the first study to be conducted by an NEI-funded collaborative clinical research group called Studies of the Ocular Complications of AIDS (SOCA). The purpose of SOCA is to facilitate and expedite clinical trials of promising drugs for treating CMV retinitis and to gather information on CMV and other ocular complications of AIDS. The AIDS Clinical Trials Group, funded by NIAID, is also collaborating in the ganciclovir/foscarnet trial.

National Institute of Environmental Health Sciences

The National Institute of Environmental Health Sciences (NIEHS) research on AIDS focuses on assessing the toxic effects of drugs used to treat AIDS, and on understanding those properties of the AIDS virus that make vaccine development so difficult.

Animal Models Define Toxic Effects of AIDS Therapeutic Drugs

The cataclysmic nature of the AIDS epidemic has led to clinical use of proposed AIDS drugs in humans before the data on animal side-effects are complete. Intramural scientists Drs. Michael Luster and Virginia Sanders head the NIEHS effort to provide the necessary animal studies through intramural and contract research. Southern Research Institute, Birmingham, Alabama, which has the largest NIEHS contract for AIDS-related studies, has completed short-term tests of numerous AIDS drugs and combinations of drugs in rats and mice; these results are now being analyzed. Preliminary analyses indicate that rodent models react to AIDS therapeutics in a manner similar to humans. For instance, both humans and rodents exhibit AZT-induced anemia.

This research is being expanded to explore the long-term toxicity of INF-alpha alone and in combination with other drugs in mice. As new treatments extend the lives of AIDS patients, treatment regimes compatible with long-term use will be needed.

Scientist Explores How HIV Mutates

The ability to produce an effective AIDS vaccine is hampered by the virus' capacity to rapidly mutate into new, equally virulent forms. Dr. Thomas Kunkel, intramural scientist, has been studying this phenomenon, which may be due to the unusually high error rate of reverse transcriptase, an enzyme crucial to the virus' ability to reproduce in human cells. By defining this process, Dr. Kunkel's research may aid development of an effective drug against this constantly changing virus. There is even the possibility that the high error rate might prove to be a weakness that can be exploited in developing clinically useful strategies.

National Institute on Aging

There is an increasing percentage of AIDS patients who are over 50 years of age. Although this group used to consist mainly of individuals who had received an HIV-infected blood product or who had been married to an infected individual, the older HIV patients now are homosexuals who were diagnosed earlier and are receiving life-prolonging antiviral therapy. A growing public interest in the effects of AIDS on older people is evidenced by the fact that AIDS and Older Adults, a fact sheet of the National Institute on Aging (NIA), was one of the most frequently requested publications in 1990.

Abnormalities Found in Immune Responses of Older AIDS Patients

NIA intramural scientist Dr. William Adler and his colleagues at the Gerontology Research Center in Baltimore have been studying HIV-infected individuals over 60 years of age. They have found that there is a more rapid loss of T cells in the older AIDS patients than in younger ones. This may be due to the combined effects of age and HIV: The production of T cells has decreased as a result of aging while the destruction of T cells has increased as a result of HIV infection. The scientists have also found that older AIDS patients lose the ability to produce antibodies against all the HIV-associated antigens. This may be due to an age-related decline in cytotoxic T cells activity, which results in less destruction of HIV-infected cells and, therefore, less release of viral antigens to trigger antibody production.

As also seen in normal aging, AIDS patients do not produce enough antibodies to prevent other infections. In AIDS patients, the disruption of antibody synthesis is related to the destructive effects of HIV on T cell function. The scientists therefore feel that any anti-HIV drugs that are developed to boost the level of immune function by promoting T-cell activity should also be useful in treating age-related immune deficiency.

National Institute of Arthritis and Musculoskeletal
and Skin Diseases

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) conducts and supports research into the arthritic, musculoskeletal and cutaneous manifestations of HIV infection, and into the relationship between the structure of HIV and its infectivity.

Test Detects Presence of HIV in Skin Graft Tissue

Skin manifestations of HIV infection include Kaposi's sarcoma and psoriasis, a skin disorder of unknown cause characterized by scaly red patches. Dr. Madeleine Duvic, an NIAMS supported researcher at the University of Texas Medical School, Houston, and colleagues have found that AZT improved psoriasis in patients with AIDS. Dr. Duvic and associates have also shown that the extremely sensitive technique known as polymerase chain reaction (PCR) could be used to detect HIV in skin graft tissue used to cover burn wounds. This finding may help to prevent the transmission of HIV in engrafted tissues.

Rheumatic Complications Like to Suppress T Cells

The rheumatic manifestations of HIV infection include certain types of arthritis, inflammatory muscle conditions which are characterized by symptoms of dry eyes and dry mouth (sicca symptoms), because of abnormalities of tear and salivary gland function and Sjögren's syndrome. Dr. Robert Winchester, an NIAMS grantee, and his coworkers at the Hospital for Joint Diseases in New York City have characterized the clinical, immunologic and immunogenetic features of a Sjögren's-like syndrome associated with HIV infection. Early in HIV infection, suppressor T cells express CD8 molecules on their surfaces. These cells may infiltrate into various tissues, producing a distinct syndrome of salivary gland enlargement, sicca symptoms, and lung involvement. Dr. Winchester and coworkers found that this distinct syndrome occurs in individuals whose immune cells carry an inherited marker known as HLA-DR-5, suggesting that the disorder is related to a genetically determined host immune response to HIV.

National Center For Research Resources

Shared facilities provided by the National Center for Research Resources (NCRR) have supported a variety of studies focused on AIDS. Funds from several NCRR programs have assisted in the search for new AIDS drugs and the discovery that AZT may be beneficial in the earliest stage of infection with the AIDS virus.

Thyroid Function Decline Warns of Advanced Illness

Progressive changes in the thyroid function of AIDS patients may increase the risk of life-threatening infections, according to NCRR grantees at the University of Southern California Medical School in Los Angeles. In AIDS patients treated at the GCRC in the Los Angeles County-USC Medical Center, Dr. John T. Nicoloff, GCRC director, and colleagues have observed a distortion in thyroid function that gets worse as the symptoms of AIDS progress.

Dr. Nicoloff and his associates have found that abnormal thyroid function in AIDS patients tends to keep their metabolism at a high rate, despite the onset of infections. A normal response during most illnesses is for the thyroid, through the release of hormones, to slow down metabolism, helping the body conserve energy needed to fight infection. In AIDS patients, however, thyroid hormones slow the body's response to illness only when they are terminally ill.

Monitoring thyroid status in AIDS patients may thus allow doctors to determine when patients are dangerously susceptible to life-threatening infections and perhaps to administer treatment to prevent infection. Thyroid abnormality may also help explain why AIDS patients tend to lose weight rapidly.

Ribozymes Cut Up HIV Genes, Disrupt Genetic Messages

A type of genetic scissors borrowed from the plant world shows promise as a way to stop the AIDS virus from multiplying inside a patient's body. NCRR grantees Drs. Karl Drlica and Fred Russell Kramer of the Public Health Research Institute in New York City, with funds from the NCRR Biomedical Research Support (BRS) Program, have begun a project to use molecules called ribozymes to snip the viral genes destroying genetic messages that the HIV needs in order to multiply.

These ribozymes, which are made inside specially engineered cells, bind to specific places on viral RNA, and then cut it. Dr. Drlica and associates are using genetic engineering to develop new kinds of ribozymes that have an improved ability to seek out and destroy RNA produced by HIV. Their research has already identified ribozymes that can destroy HIV RNA that has been synthesized in bacteria.

National Center for Nursing Research

Research on HIV infection supported by the National Center for Nursing Research (NCNR) focuses on better methods of health care for patients and better ways to help patients, care givers and families minimize dysfunction and suffering due to physical symptoms and psychosocial problems caused by HIV infection and its treatment.

Study Addresses HIV-Related Nutritional Problems

With better medical treatments for HIV infection and AIDS, many patients may live for years with symptoms that require expert nursing care. These commonly include weight loss, decreased appetite, and other nutritional disorders. The first study in the newly established Collaborative Intramural Program (CIP) conducted with the NIAID addresses these HIV-associated nutritional problems.

NCNR intramural scientist Dr. Mary Ropka and her colleagues are documenting the types and extent of nutrition-related changes occurring at different stages of HIV infection. They are investigating the causes of these changes and the relationship between nutritional status and immune function. About 90 patients who are currently enrolled in NIAID studies at the NIH Clinical Center will participate in the NCNR nutrition study.

Fogarty International Center

The Fogarty International Center (FIC) continues to develop two AIDS-related international research training programs initiated in FY 1988. The purpose of these programs is to expand the numbers of highly trained epidemiologists, postdoctoral scientists, and clinical investigators worldwide, particularly in developing countries.

One program trains foreign scientists from developing countries in epidemiology, while the other provides postdoctoral research opportunities for U.S. and foreign scientists. Both programs support training in the United States and foreign countries. The programs operate through FIC grants to U.S. institutions, which then select participating scientists. During their second year, the programs were expanded to include scientists from Eastern Europe and the Soviet Union. Altogether, 37 countries participated in these programs during FY 1990.

FIC also has collaborated with the NIAID to further develop the International Network for AIDS Research and Training, which links the major international AIDS programs of the NIH, the U.S. Agency for International Development, and the World Health Organization (WHO). The network was formed in FY 1989 to prevent duplication of efforts by facilitating the coordination of its participants' activities. It also identifies research and research training needs, and helps organize responses to emerging problems.

Additionally, FIC cooperated with the WHO/Global Programme on AIDS to establish the Global HIV/AIDS Network. The network is an electronic computerized system that ties together the Fogarty-supported AIDS research and training programs with WHO offices to rapidly disseminate the latest AIDS surveillance data and other AIDS-related information.

National Library of Medicine

The NLM's collection of some four million items, its MEDLARS computerized databases, and its Regional Medical Library program are the pillars of a national health information network designed to ensure timely dissemination of scientific and medical information about AIDS to the biomedical community.

The Library currently sponsors three AIDS-related online databases on its MEDLARS network: AIDSLINE, AIDSDRUGS, and AIDSTRIALS. The Library also publishes the monthly AIDS Bibliography, the latest in a series of AIDS "literature searches" that began in 1983. The Bibliography, with citations to journal articles and books as well as audiovisual materials, covers the spectrum of areas of AIDS concerns--preclinical, clinical, epidemiological, diagnostic, and prevention. It is sold on subscription by the Government Printing Office.

AIDSLINE Links Users to More Than 40,000 AIDS References

AIDSLINE is an online computer file of more than 40,000 references to the published literature on AIDS, dating back to 1980. It is updated weekly and is growing at the rate of about 800 new citations a month.

Databases Provide Information on Clinical Trials of AIDS Drugs and Vaccines

In 1989, two new databases, AIDSDRUGS and AIDSTRIALS, were added to the MEDLARS system. They provide online access to current information from NIAID and FDA on clinical trials of AIDS drugs and vaccines, including the general criteria for patient participation in those trials. The FDA provides information on privately sponsored experimental tests of efficacy, and NIAID provides information about NIH-funded safety and efficacy trials.

PHS also makes this information available through NIAID's toll-free, confidential telephone service (1-800-TRIALS-A). Having the databases available on NLM's system, however, gives those with a repeated need for such information--physicians and community-based AIDS organizations, for example--the option of performing their own searches directly, online.

Office of The Director

The Office of AIDS Research (OAR) in the Office of the Director, NIH, continues to support the AIDS Program Advisory Committee, the group of non-Government experts that advises the Director, NIH, on priorities for AIDS research at NIH. In FY 1990, the Committee met to examine the scientific areas of immunopathogenesis, drug development, vaccine research, pediatric AIDS, epidemiology, central nervous system disease, and clinical trials and their priorities in the NIH budget. In addition, they advised the Director, NIH, and the Secretary, HHS, on issues surrounding the funding of AIDS research, the proposed conflict of interest guidelines, and restrictions placed on importation of nonhuman primates.

In FY 1990, the OAR implemented the NIH AIDS Research Loan Repayment Program (LRP), as directed in Public Law 100-607, enacted by the United States Congress in November 1988 to establish a program of educational loan repayment to attract additional individuals with graduate degrees (M.D., Ph.D., D.D.S. or others) into AIDS research at NIH. The LRP is designed to counter the growing economic disincentives to embarking on research careers. It pays directly to participants' lenders a maximum \$20,000 per year toward the participants' qualifying educational debt, during a minimum 2-year service period. After review by NIH's Loan Repayment Advisory Committee, 19 applicants were approved for program participation in six Institutes.

The Office of the Director continues to support the intramural AIDS targeted antiviral program. This rational approach to drug design includes structural and functional studies of HIV proteins, molecular and cellular studies of the virus, and development of antiviral agents directed at specific molecular targets. Researchers are using the techniques of x-ray crystallography and nuclear magnetic resonance to determine the three-dimensional structures of various components of the virus. NIH's newly opened Protein Expression Laboratory has begun to produce HIV proteins through recombinant DNA techniques for use by NIH scientists in structural, biochemical, and pharmacological studies.

The OAR is responsible for the coordination of all NIH AIDS international activities. Working with the Institutes, the OAR provided support for participation by 22 scientists from the U.S.S.R. and seven from other Eastern European countries in the VI International Conference on AIDS held in June, 1990. The intent was to provide the opportunity for scientist-to-scientist dialogue and a basis for scientific collaboration. The scientists represented a wide variety of expertise from areas such as immunology, virology, and clinical management.

Future Directions

Expansion of HIV and AIDS-related research is anticipated in many areas including clinical manifestations, pathogenesis, therapeutics, and drug and vaccine development. As important discoveries emanate from research on early intervention and vaccine development, emphasis is shifting to early detection of HIV seropositivity so as to implement appropriate therapeutic interventions.

Basic research will continue to play a critical role in combatting the AIDS epidemic, as it expands our understanding of the mechanisms of infection, viral activation, and immune system suppression.

Drug development will continue to be a high priority in AIDS research as scientists continue to screen large numbers of compounds in the laboratory and to use sophisticated techniques of structural biology to design targeted anti-HIV agents. In addition, vaccines will continue to be tested for their safety and efficacy, as vaccine development is proving to be an effective avenue of AIDS research.

Developing programs, such as Parallel Track, the CPCRA and other NIH outreach programs, will expand AIDS clinical trials and educational services, improve access to promising therapies and provide optimal care for those infected with HIV. Special efforts are being generated to include more HIV-infected women, independently of their relationship to pediatric HIV cases, in clinical trials.

FOOD AND DRUG ADMINISTRATION

ACQUIRED IMMUNE DEFICIENCY SYNDROME

As the largest consumer protection agency of the Federal Government, FDA plays a major role in the Federal Government's response to the AIDS epidemic. FDA is responsible for assuring the safety and effectiveness of drugs, biological products, and medical devices and has responsibility for safeguarding the nation's blood supply.

Therapeutic Agents

Applications for candidate drugs and biologics as therapeutic agents in the treatment of AIDS and AIDS-related diseases continue to receive the highest priority (1AA designation) in FDA's review system for timely and expeditious review.

Retrovir (zidovudine, formerly known as AZT) stands as the first therapy to go completely through the AA designation process, created in June, 1986, as an extension of the existing classification system for review of Investigational New Drug Applications (INDs) and New Drug Applications (NDAs). Timely reviews led to the approval of a Retrovir syrup formulation in September, 1989 and an intravenous dosage form in February, 1990. FDA also approved expansion of the labeling indications for Retrovir in May, 1990.

The expedited review process has also resulted in the licensure of human interferon Alpha 2 for the treatment of AIDS-related Kaposi's Sarcoma (November, 1988); the approval of aerosolized pentamidine for prevention of Pneumocystis carinii pneumonia (June, 1989), ganciclovir for use in the treatment of cytomegalovirus retinal infections in persons with AIDS (June, 1989), fluconazole for use in the treatment of candidiasis and cryptococcal meningitis (January, 1990), and r-erythropoietin for treatment of zidovudine-related anemia (December, 1990).

Six Treatment INDs for products to treat AIDS-related diseases have been approved for study since the Treatment IND regulations became effective in June, 1987. Two remain under active study: Trimetrexate, an experimental drug for treating Pneumocystis carinii pneumonia; and, Dideoxyinosine, known as ddI or Didanosine, to treat adult patients who cannot take Retrovir. In addition, Didanosine along with Dideoxycytidine, or ddC, is also available through expanded access open safety protocols.

In October, 1988, FDA issued interim regulations designed to further expedite marketing approval by shortening the clinical testing process. FDA worked with PHS representatives, community advocates, industry representatives, the research community, and the interested public in developing the parallel track proposal.

These proposed regulations will make promising therapeutic agents still under study more widely available to persons with AIDS or AIDS-related conditions who have no therapeutic alternatives and who cannot participate in the controlled clinical trials.

Many of the ongoing clinical trials are now listed in the AIDS Clinical Trials Information Service (ACTIS), a central resource providing current information on federally and privately sponsored clinical trials. More than 100 protocols are now listed through FDA. This information is available to all persons through toll-free telephone service and to National Library of Medicine subscribers through the AIDSTRIALS data base.

Within FDA, the Center for Drug Evaluation and Research (CDER) and the Center for Biologics Evaluation and Research (CBER) bear the primary responsibility for conducting AIDS-related product research, as well as review activities. The Division of Cytokine Biology, within CBER, includes several laboratories devoted to in-depth study of cell biology, immunology, and other possible keys to understanding HIV and its many ramifications.

In April, 1990, the Division of Clinical Pharmacology was established within CDER to study the "regulatory" clinical pharmacology of such drugs as ddI and zidovudine. This division has begun to study the effects of zidovudine and other antiviral agents on red blood cells, white blood cells, and platelets when grown in culture. The purpose of the study is to develop methods to forecast appropriate dosage levels in order to minimize the toxicity of such drugs.

FDA assists community-based research efforts directed at AIDS. This research is proving to be a valuable method for gathering safety and efficacy data on experimental therapies, an example of which is aerosolized pentamidine, where community physicians in the San Francisco County Community Consortium Initiative provided the clinical data used to support that drug's approval. FDA is also working closely with the American Foundation for AIDS Research (AmFAR)-funded community-based research groups and their Community-Based Clinical Trials Network.

FDA is responsible for post-marketing surveillance which involves the monitoring of adverse drug reactions and drug use data. As more AIDS therapies become available, there is an increased need for knowledge about how approved therapies are used in clinical practice. Evaluation of these experiences will become increasingly difficult as approved AIDS therapies become more complex, and the potential for adverse reactions resulting from the use of multiple therapies increases.

Vaccines

FDA is continuing its efforts to expedite the development and testing of vaccines for the prevention of HIV infection. While

there is currently no effective vaccine available, eight IND applications have been received, and several have been approved for Phase I clinical trials.

In studying the immunology of AIDS, FDA has demonstrated that some proteins of HIV are targets for human immune responses and could be used in developing a vaccine against the virus. A rapid and sensitive microneutralization assay has been developed and is being used to evaluate the specificity of immune responses induced by candidate vaccines. Additional studies are producing information necessary for the evaluation of vaccine safety, efficacy, and potency. Also in progress are studies to characterize cellular immune responses to HIV antigens. Cell-mediated responses may come to play an important role in vaccine-mediated disease prevention.

Applied research programs on viral immunology, pathogenesis, and molecular biology are underway to meet specific identified laboratory and review needs. Agency scientists have cloned and expressed HIV genes in bacteria, eukaryotic cells, and replicating viruses. Among other applications, this research is used to study potential mechanisms of action of vaccines and the immunology of HIV infections.

In March, 1990, FDA granted permission for expanded clinical testing of an experimental inactivated virus vaccine being studied for its potential to counteract infections with HIV-1. The multicenter trials are testing the vaccine as a treatment, not a preventive, in HIV-infected persons who have not developed systems of AIDS or AIDS-related complex. This is the third such experimental vaccine for use as a treatment for HIV infection to be approved for human testing in the U.S. The first, a genetically-engineered vaccine made from an insect virus was approved for human trials in August, 1987 and the second, a genetically-engineered vaccine made from the vaccinia virus, was approved for human trials in November, 1987.

FDA maintains a functioning partnership between the regulatory scientists and reviewers in FDA and their counterparts from outside organizations involved in vaccine development. FDA is defining issues that should be addressed prior to initiation to Phase I vaccine clinical trials and in anticipation of efficacy studies. The Agency has frequent joint meetings with manufacturers of candidate vaccines which help to facilitate preclinical and clinical development and IND review.

Diagnostic Reagents and Test Kits

Progress continues on the development of satisfactory test methodologies for detection of antibody to the human immunodeficiency virus. Currently, there are eleven licensed manufacturers of in vitro test kits for the detection of antibody to HIV-1 and one for the detection of antibody to HIV-2. These products include ELISA screening tests, one particle-agglutination

screening test, and two Western blot tests. There is also one licensed manufacturer of an in vitro test kit for the detection of proteins, or antigens, of HIV-1. A number of applications for new kits and amendments are pending.

FDA revised the package insert labeling of HIV antibody test kits to permit a claim for clinical diagnostic use. This has made testing more widely available for purposes other than the screening of blood.

In August, 1989, FDA licensed the first diagnostic kit to detect the presence of HIV-1 by directly detecting the antigens of the virus. This new HIV-1 antigen test helps physicians diagnose and follow the medical status of HIV-infected persons. It is not intended for use in screening blood or plasma donations.

In May, 1990, FDA granted a license for the Recombigen (R) HIV-1 EIA AIDS antibody detection kit. This test, designed for high volume screening sites such as hospitals, blood banks, and reference laboratories, takes approximately 2 hours to perform and its high specificity provides a false-positive rate of only 0.03 percent.

In June, 1990, FDA approved the Novopath HIV-1 Immunoblot test for the detection of antibodies to individual proteins of HIV-1. This test, nearly five times faster than comparable tests using the same technology, is put into a ready-to-use kit with which confirmation can be obtained in less than 3 hours as compared to other Western blot assays which require 15 hours. FDA approval will allow the use of this product in virtually any laboratory or blood bank in the U.S.

For a number of years, the medical device industry has shown an interest in marketing test kits for home use, involving self-collection of blood sample and mailing to a laboratory for AIDS antibody testing. Because of the uncertainties surrounding such a test (i.e. improperly drawn sample, risks involved in mail delivery, patient confidentiality, and provision of counseling), FDA published criteria to be met for the approval of home blood collection kits. As far as FDA is concerned, this criteria remains valid. FDA is willing to allow manufacturers to proceed to conduct studies under investigational device exemptions (IDEs) and submit PMAs on kits that the Agency would find acceptable for review.

Blood and Blood Products

FDA has an ongoing responsibility to ensure the safety of the nation's blood supply. The protection of this resource is vital.

Although the risk of acquiring HIV by transfusion of blood has almost been eliminated with blood and donor screening efforts, FDA is continuing the 100 percent inspection of FDA-regulated blood donor facilities launched several years ago in order to further

reduce this risk.

The Agency continues to promote the use of autologous, instead of homologous, blood for elective procedures that may require transfusion. In March 1989, the Agency issued recommendations on the use of autologous blood.

HIV antibody testing, continuing in all blood banks, donor centers and plasmapheresis centers, has been augmented by the licensed Western blot test which serves as the basis for reentry of blood donors tentatively deferred because of nonrepeatable, false-positive results from initial screening. Use of the Western blot has upgraded the specificity of information derived from donor screening.

In order to focus attention on issues concerning blood screening and the safety of injected blood products, FDA has created a Laboratory of Retrovirology. Among other things, the laboratory is engaged in research on detection of HIV infection by culture, gene amplification, and inactivation of virus in the manufacture of blood products. These include: studies on the adequacy of the processes used to prepare anti-hemophilic factor (Factor VIII) and immunoglobulin in the inactivation of HIV; the inactivation of HIV in cellular and fresh plasma components for transfusion; and, the effectiveness of viral inactivation strategies currently in use for commercially fractionated plasma derivatives.

FDA has developed contracts for the management of large serum repositories which can be used to validate the sensitivity of commercial tests for HIV and HTLV-1 antibodies.

The Agency has published and distributed standards, guidelines, and recommendations dealing with protecting the blood supply from transmission of infectious agents, including regulations ensuring that blood establishments enroll in proficiency testing programs. In addition, FDA provided a formal training program on anti-HIV testing for all FDA inspectors in the field.

Medical Devices

In its ongoing responsibility to assure the safety and effectiveness of medical devices, FDA is continuing a program that concentrates on preventing the transmission of HIV and AIDS-related diseases through barrier products such as condoms and surgical gloves, and commonly-used clinical devices. FDA is surveying the methods of disinfection of clinical devices to learn how sterilization procedures may be improved and is working with the CDC and device manufacturers on ways of minimizing risk.

FDA has been working with manufacturers of condoms to improve the instruction for use of this user-dependent product. FDA has also notified the marketers of natural membrane (skin) condoms of the need to state explicitly the intended use of their product,

i.e. contraception, and to address the limitations of the product noting that these condoms are not intended for prevention of sexually transmitted diseases.

Studies are currently being performed to evaluate the effect of environmental factors on latex. FDA has developed a document for use by condom companies in requesting modification of their labeling to include an expiration date and that the date be based upon real-time testing rather than accelerated aging. Based upon research on the compatibility of latex with oil-based products such as vegetable and mineral oils which are contained in some vaginal antimicrobial products, product labeling is being reviewed to assure adequacy to address incompatibility.

In the field, FDA is inspecting manufacturers and processors of both domestic and foreign-made condoms to ensure conformance with FDA's criteria for acceptability. Since implementation of this program, FDA has tested over 200,000 condoms from about 730 batches of condoms. These efforts are leading to increased quality control by manufacturers.

During 1989, FDA modified its regulatory approach to latex and vinyl gloves by revoking the premarketing notification exemption. This action allows FDA to better monitor the initial marketing and subsequent manufacturing changes of these devices. FDA also conducts research on glove barrier effectiveness and glove use.

FDA has developed guidance on the preclinical and clinical testing of female barrier contraceptive devices also intended to prevent transmission of sexually transmitted diseases, including AIDS. The document, entitled "Premarket Testing Guidelines for Female Barrier Contraceptive Devices Also Intended to Prevent Sexually Transmitted Diseases" was prepared to assist manufacturers in preparing their premarket submissions, thereby expediting device study and evaluation for market release.

FDA is currently surveying actual sterilization/disinfection practices of medical devices in the health care environment.

CENTERS FOR DISEASE CONTROL

Human Immunodeficiency Virus (HIV)/Acquired Immunodeficiency Syndrome (AIDS)

As of November 30, 1990, a cumulative total of 157,525 AIDS cases had been reported to the Centers for Disease Control (CDC), including 2,734 cases in children less than 13 years of age. Over half of all reported cases have died. Of the 2,734 children reported, 739 cases, or 27 percent, were reported during the past year. As of November 30, 1990, 39,744 cases were reported during calendar year 1990. Racial and ethnic minority populations continue to be disproportionately affected by the new epidemic. Blacks and Hispanics account for 27.8 percent and 15.7 percent, respectively, of the reported cumulative adult AIDS cases. Blacks represent 52 percent and Hispanics 30 percent of the pediatric cases.

In fiscal year 1991, CDC will continue to conduct activities to further clarify the epidemiology and natural history of HIV infection through surveillance of AIDS cases, seroprevalence surveys and studies of HIV infection, epidemiologic studies, and laboratory investigations. In addition, CDC will intensify prevention strategies and increase the transfer of technology designed to prevent and control the transmission of HIV. These activities include the following:

- o National surveillance of AIDS cases;
- o Pilot studies of HIV surveillance through State and local health departments;
- o Domestic and international epidemiologic studies to identify risk factors and further define and quantify cofactors and modes of transmission; development and evaluation of prevention strategies;
- o Investigation and evaluation of new serologic and other diagnostic tests;
- o Research on an improved animal model for HIV infection;
- o Collaborative vaccine development and evaluation;
- o Transfer of technology to the medical and public health communities to facilitate early intervention in HIV infection.

CDC will continue to provide HIV prevention information and education to individuals, health care workers, high-risk groups, scientific and public health communities, and the public in support of the overall goal of preventing HIV infection. Cooperative agreements will continue with State and local health departments to conduct active HIV/AIDS surveillance. Cooperative agreements will continue to support over 500 sentinel surveillance sites to determine seroprevalence of HIV infection through State and local health departments, other public facilities, and selected private institutions included in CDC's National HIV Seroprevalence Surveys (Family of Surveys).

SURVEILLANCE

CDC will monitor, analyze, and project national trends for HIV infection and AIDS incidence by geographic area and groups at increased risk. Among other purposes, active surveillance will help clarify risk factors and patterns of transmission, and will provide data used in the formulation of prevention strategies, public policy, and the allocation of resources at all levels to combat the epidemic.

EPIDEMIOLOGIC STUDIES

Since 1981, CDC has conducted specialized, intensive epidemiologic studies to: contribute to understanding the natural history of HIV; investigate modes of HIV transmission; identify those at risk; document cofactors associated with increased risk for acquiring the infection; and provide HIV risk-reduction guidelines and prevention recommendations applicable to large segments of society. CDC-sponsored investigations include studies of men who have sex with men, injecting drug users (IDUs), persons with hemophilia, transfusion-associated AIDS cases, sex partners of persons with HIV infection or at increased risk for the disease, children with AIDS, newborns with HIV infection, HIV-infected women of childbearing age, infected pregnant women, cases related to heterosexual transmission, and female prostitutes.

To further define risk factors for HIV transmission and to clarify the natural history of infection, CDC will initiate, continue, or expand, studies of: pregnancy outcomes, newborns acquiring the virus from their mothers; families of children with transfusion-associated HIV infection; increased deaths among IDUs from respiratory conditions thought to be associated with HIV infection; AIDS patients reported with undetermined risks; heterosexually transmitted HIV infection; transfusion-associated HIV infection; risk factors for transmission among a cohort of men who have sex with men in San Francisco; sex partners of men who have sex with men; family members of persons with AIDS and HIV-related infections to further examine transmission factors; donors of blood to recipients who develop transfusion-associated HIV infection; recipients of blood and organ transplants from donors later found to be HIV-infected; transmission in prisons; infection in female prostitutes; patients with lymphadenopathy syndrome (LAS) to determine any changes in risk factors for developing AIDS; neurologic aspects of HIV infection; surveillance and epidemiologic investigations of persons infected with HIV-1 and HIV-2 transmission in Africa; investigations of HIV transmission factors in Thailand; and risks of HIV infection in aerosols generated by surgical/operative procedures.

LABORATORY INVESTIGATIONS

CDC will continue laboratory investigations of HIV to: provide viral isolation, serologic and immunologic support for epidemiologic and seroprevalence surveys and studies; assess sensitivity and specificity of serologic tests; develop and evaluate new screening (polymerase chain reaction) and diagnostic tests; assess differences among virus isolates from various geographic areas for possible variability in patterns of host response and pathogenicity; determine whether detection of virus protein and/or nucleic acid sequences are useful in rapid diagnosis of infection; correlate clinical and epidemiological findings with antibody to HIV and positive cultures of this virus; determine immunologic responses to infection with HIV; document the susceptibility of HIV to disinfectants and sterilizing procedures; clarify the natural history of infections in primates and other animals infected with HIV; accelerate the development of therapeutic technologies through animal model investigations; and participate in vaccine development and evaluation.

Resources will be focused upon improving screening and diagnostic technologies to identify persons earlier in the course of their infection. This effort will improve the safety of the world's blood supply, enhance clinical care through early intervention, and improve HIV prevention and control outcomes.

NATIONAL LABORATORY EVALUATION PROGRAM

A National Laboratory Evaluation Program has been developed to assess the capability of the Nation's laboratories in performing currently available tests used in prevention and control of HIV infections and AIDS. Currently, there are over 1,400 laboratories enrolled in this voluntary program.

Performance evaluation samples have been shipped to the participants periodically and results are being analyzed. Additional evaluation and improvement activities planned include: identification and characterization of HIV testing laboratories; shipment and analysis of performance evaluation serum panels; correlation of characteristics with laboratory performance; development of methods of estimating sources of error in the entire testing process; and implementation of intervention strategies.

CDC continues to develop and modify prevention recommendations for individuals at increased risk of infection, health-care workers, and the public. PHS prevention recommendations to reduce the risk of HIV transmission were first issued in November 1982, for clinical, laboratory, and animal research workers and in March 1983, for blood donors, members of risk groups, and sex partners. A total of 59 guidelines related to prevention of AIDS and HIV transmission have been developed and distributed, with 10 published in 1990. Future guidelines will be based on ongoing epidemiologic research intended to clarify and quantify the risk of HIV groups and to identify specific behaviors, factors, or cofactors which increase susceptibility. Dissemination of information and recommendations is facilitated by CDC's continued financial and technical assistance for an information interchange system among city governments through the U.S. Conference of Mayors. The interchange system will make timely and appropriate information about HIV infection available to mayors and local health officials, especially in heavily affected cities.

CONTROL STRATEGIES

The strategy to control the spread of HIV is influenced by five crucial facts: (1) no effective therapies exist to eliminate virus from an infected person; (2) no vaccine exists to prevent susceptible persons from acquiring HIV infection; (3) infected individuals may transmit the virus throughout their lifetime; (4) spread of the virus results from a limited number of personal behaviors, which, when altered, can reduce or prevent transmission of the virus; and (5) HIV infection represents the first contemporary infectious disease causing significant morbidity and mortality for which public health prevention and control measures and individual behavior change remain the major intervention tools. Related control mechanisms include: (1) expansion of drug abuse treatment capacity; (2) expansion of STD prevention programs; (3) provision of contraceptive information to infected women who are identified through HIV counseling and testing programs; (4) continued testing to ensure a safe blood supply; and (5) increased education and reinforcement to discourage at-risk individuals from donating blood.

The goal of the control strategy, therefore, is to reduce HIV transmission by influencing the behavior of people in three specific population groups. The primary effort is to apply individually-targeted health education messages to persons who are already infected so they will adopt behaviors that reduce their risk of infecting others. The second is to deliver risk reduction messages that will help prevent infection in people who are uninfected, but whose current personal behaviors place them at high risk of acquiring an

infection. The third effort is to reach the general public with timely and accurate information that defuses unjustified fears, facilitates rational behavior toward all aspects of the HIV epidemic and promotes constructive support for public health control efforts. Preventing the spread of HIV requires the successful implementation of two major strategies. The first strategy attempts to discourage persons from adopting risky behaviors by promoting health behaviors through group level interactions, such as school-based prevention programs. The second strategy attempts to reach individuals at high risk at the personal level, helping them to better understand their vulnerability to infection, promoting less risky behavior and alternate safe behaviors, and helping them gain the skills and support to maintain a low-risk lifestyle. The focus of program services at the personal level is to provide both high-risk individuals, and their partners, with education tailored to their unique situations and particular needs for assistance.

In fiscal year 1987, the AIDS Health Education/Risk Reduction (HE/RR) and Counseling and Testing Site (CTS) cooperative agreements were consolidated as the primary components of the HIV Prevention Program. Further consolidation occurred in fiscal year 1988 with the addition of surveillance activities, including a seroprevalence component, that were previously funded as a separate program.

In addition to increased HE/RR and expanded Counseling, Testing, Referral and Partner Notification (CTRPN) activities, the prevention component includes a minority initiative and public information campaign component. Agreements are in place with 50 States, the District of Columbia, the Commonwealth of Puerto Rico, seven territories and six municipalities.

Since health education is the primary strategy for controlling transmission of HIV, it is essential to identify the most effective methods of applying these techniques to test them and other evolving control measures under actual program conditions, and to disseminate information to all States. To these ends, CDC has awarded six cooperative agreements supporting ongoing community-based demonstration projects for HIV prevention and risk reduction. These projects focus on development, implementation and evaluation of HIV prevention interventions among hard-to-reach populations. Findings provide important insights into how prevention and early intervention can reach and assist persons at high risk to initiate and sustain safe behavior. The findings are routinely disseminated to the prevention projects.

RACIAL AND ETHNIC MINORITY POPULATIONS

Because AIDS affects racial and ethnic minority populations disproportionately, CDC will continue to provide to State and local health departments funds which are specifically targeted to this important group. In 1990, more than 315 community-based organizations (CBOs) providing services to racial and ethnic minority populations were supported through this mechanism. In 1990, support was also provided to 28 national and regional minority organizations. In addition, funds are being provided to the United States Conference of Mayors (USCM) to support HIV information exchange and to expand funding to minority-oriented CBOs conducting HIV information programs. Since 1985, the USCM has awarded CDC funds to 114 CBOs, most of which direct HIV prevention programs to minority populations. In 1990, funds for HIV information and education were also awarded directly to 66 local minority CBOs in the metropolitan areas having the highest cumulative number of reported

AIDS cases among racial and ethnic minority populations. Funding and technical assistance will continue to be provided to these CBOs in 1991.

NATIONAL PARTNERSHIP PROGRAMS

Persons with hemophilia are a special group at high risk for HIV infection and AIDS. Consistent with Congressional intent, CDC provides funding through an interagency agreement with the Human Resources Services Administration (HRSA) for a national HIV educational effort directed to persons with hemophilia and their sex partners. CDC collaborates with the National Hemophilia Foundation and HRSA in conducting these activities through the national network of Comprehensive Hemophilia Treatment Centers. This major effort will continue in fiscal year 1991.

Collaboration between CDC and the American Red Cross (ARC) continued in 1990 through the existing cooperative agreement between these organizations. The American Red Cross (ARC) continued implementation of its comprehensive information and education program, using \$7.0 million provided by CDC through an existing cooperative agreement. In fiscal year 1990, ARC established a national network of people from civic and minority organizations and from its own 2,853 chapters who have been trained to deliver credible education programs within communities of every size. Its Spanish television docudrama, "Mi Hermano," received extensive national and international airings and is estimated to have reached more than 30 million viewers. A State Networks Project was expanded to include 41 States and the Commonwealth of Puerto Rico and is helping to establish integrated, collaborative education programs in those States.

In addition to providing training, educational videos, and more than 40 million brochures to assist local chapters in their community-based education programs, ARC awarded \$1.3 million in chapter grants in support of innovative, promising and/or minority targeted education efforts.

In collaboration with ARC and several other CDC grantees (National Leadership Coalition on AIDS, George Meany Center for Labor Studies, and the Service Employees International Union), a major effort was launched in fiscal year 1990 to develop a coordinated program for stimulating greater participation in HIV-related issues by American businesses. A March 1990 meeting in which chief executive officers from more than 400 American corporations were in attendance, provided President Bush with a forum for the first public policy address on AIDS by an in-office U.S. President. A survey of more than 1,000 small businesses (under 100 employees) indicated that less than 12 percent of those businesses have provided their employees with some form of information or education about HIV and AIDS. The CDC staff are also working to strengthen relationships among the major religious organizations in the United States to facilitate systematic, coordinated HIV prevention and social service programs nationwide.

SCHOOL HEALTH EDUCATION

CDC continues to support a program, School Health Education to Prevent the Spread of HIV Infection, designed to help school personnel and others plan, implement and evaluate effective education about AIDS and HIV infection for youth. The schools are a particularly important focus for HIV prevention efforts as more than 45 million young people are currently enrolled in some 100,000 elementary and secondary schools across the country and more than 12 million additional students are enrolled in colleges and universities. The program enables schools, and organizations serving youth not in school, to identify and develop effective HIV prevention educational strategies that are consistent with community values and needs.

CDC has established cooperative agreements with 23 national organizations to increase the number of schools, and agencies serving youth not in school, that provide effective HIV prevention education. Several of these organizations target black and/or Hispanic youth, incarcerated youth, runaway youth, and college and university populations.

Cooperative agreements have also been established with 55 State and territorial and 16 local education agencies in jurisdictions with the highest cumulative number of reported AIDS cases to provide locally-determined prevention education for school-aged populations. Two State and one local education agency receive additional funding to support training/demonstration centers. These centers provide training to State and local education agency representatives from across the country on how to implement effective HIV education in their school systems.

In fiscal year 1990, CDC began a new program to increase the number of colleges and universities that provide HIV prevention education and to increase the number of college students who receive HIV prevention education. Five universities in selected States with a high incidence of reported AIDS cases received financial and technical assistance from CDC to establish an HIV education consortium among other schools within the State. Each funded school is planning to conduct the following activities: (1) disseminate materials; (2) train staff and students; (3) coordinate HIV prevention programs in the State; and (4) monitor HIV prevention education.

The AIDS School Health Education Subfile, part of the Combined Health Information Database, became operational in 1987. As of April 1990, the annotated bibliography of the AIDS Subfile contained over 600 abstracts of curricula, policies, teaching materials, and programs related to AIDS and HIV. The subfile provides educators across the Nation with ready access to a wide variety of materials developed at the national, State and local levels.

NATIONAL PUBLIC INFORMATION PROGRAM

The national AIDS information campaign, "America Responds to AIDS" (ARTA) which was launched in October 1987, has attained a level of public exposure that is unprecedented in public health history. During its first three years of program activity, the ARTA campaign converted \$7.4 million in costs for developing public service advertising and collateral information materials into \$58.5 of donated broadcast airtime from 52,454 airplays. Based on Nielson survey data on TV viewership, this has resulted in an average of 26 viewer exposures for every American adult from TV public service announcements (PSAs) alone. The AIDS Supplement to the National Health Interview Survey indicates that the American public has grown in its understanding of AIDS over these same three years, improving on all measures of transmission knowledge and belief, but remaining disturbingly unconvinced about the improbability of casual transmission. According to a randomized survey of adult populations in France, the United Kingdom, and the United States conducted by the Project Hope Center for Health Affairs and published in July 1990, adult citizens in the United States report greater frequencies of exposure to AIDS-related information from a broad spectrum of mass media vehicles, and also report higher rates of HIV prevention specific behavioral changes, a result which the researchers say is associated directly with the relative levels of media exposure.

Several factors have contributed to the uncommon level of public impact that the ARTA public service advertising campaign has generated. First, the public service advertising activity has been integrated within the largest health communications system that the Public Health Service has ever been called on to establish--a demand driven system that was built in response to a deluge of requests for answers and materials to dispel the myths and anxieties that surrounded a new, mysterious destroyer of primarily young people. The system includes a national toll-free telephone hotline that has provided live information and referral services to more than 5 million callers in 3 years through its English, Spanish, and TTY (teletypewriter/telecommunications devices for the deaf and hearing impaired callers) lines; a National AIDS Information Clearinghouse that has distributed more than 60 million information documents and responds to more than 40,000 requestors annually with information from its clinical trials, education materials, and AIDS resources databases; a national network of public, private, and voluntary partners who assist in developing and disseminating campaign-related themes and materials; PSAs which are specifically developed for local tagging and distribution to supplement national or network airplays; and, the creation of an applied research and evaluation unit at CDC which conducts consumer level testing on campaign materials to determine and to enhance their effectiveness in changing consumer perceptions and willingness to take appropriate action. Finally, a program of training and technical assistance which has been carried out with the assistance of the National Association of Broadcasters, has brought campaign themes, messages, and materials to the attention of local media news and public service directors, in collaboration with State and local health officials who are able to articulate localized AIDS issues and adapt campaign materials to local needs.

In fiscal year 1990, a feasibility study was completed to determine the wisdom of purchasing airtime and print space could be evaluated in regard to a mass communication campaign's effectiveness for influencing high-risk populations that are traditionally difficult to reach. The contractor that completed the study has concluded that such a study is both feasible and desirable, and has provided a detailed set of possible study procedures and protocols.

A preliminary series of meetings were held with entertainment industry executives, producers, and writers to explore opportunities for using various media to incorporate HIV prevention and compassion themes and messages within television and movie story lines. Consultations were obtained from communications professionals who have successfully utilized such media for modeling and conveying positive health and social responses. In 1991, CDC will refine its strategies for enhancing the use of entertainment media for health promotion purposes.

PROGRAM ACCOMPLISHMENTS FOR 1990

The following are highlights of achievements in fiscal year 1990:

A. Epidemiology and Surveillance

1. Developed and distributed the "CDC Plan for Preventing Human Immunodeficiency Virus (HIV) Infection - A Blueprint for the 1990s."

2. Conducted epidemiologic studies and analyses of HIV infection in long-term survivors of HIV infection, men who have sex with men, healthy males with lymphadenopathy, injecting drug users (IDUs), persons with hemophilia, dialysis patients, transfusion-associated AIDS cases, pediatric AIDS cases, sex partners of persons with AIDS or at increased risk for infection, and health-care workers. Studies examining the risk factors for transmission associated with heterosexuals and female prostitutes were also conducted.
3. Collaborated with the Government of Zaire, the National Institute of Allergy and Infectious Diseases (NIAID), and the Institute of Tropical Medicine (Belgium), to conduct active AIDS surveillance, epidemiologic studies, and laboratory investigations in support of Projet SIDA HIV-related projects.
4. Established an agreement with the Ministry of Health, Government of Thailand, to collaborate on HIV/AIDS epidemiologic and laboratory research and prevention activities.
5. Reviewed and funded applications for AIDS surveillance and seroprevalence activities from more than 60 State, local, and territorial health departments.
6. Managed a contract for mathematical and computer simulation models to describe both the transmission and spread of HIV infection and the incidence of AIDS associated with routes of transmission.

Models will be used to assist in evaluating differences among risk behavior groups and geographical regions in the development of the HIV epidemic.
7. Developed and published estimates of current and past HIV prevalence for the United States and predictions for AIDS cases through 1993.
8. Conducted National HIV Seroprevalence Surveys (Family of Surveys) through State and local health departments and additional organizations to reach selected U.S. populations including: military recruits, American Red Cross blood donors, STD clinic patients, IDUs, family planning clinic patients, childbearing women, Job Corps applicants, prisoners, migrant workers, college students, and other populations. Published a report on findings from these surveillance activities through 1989.
9. Produced and distributed a cumulative monthly surveillance summary of AIDS cases reported to CDC.
10. Increased the number of studies of pediatric AIDS cases and transmission, including expanded perinatal transmission studies and development of a comprehensive pediatric AIDS case report form.
11. Continued sentinel hospital-based surveillance in 39 hospitals to determine prevalence and trends of HIV infection in patients.

B. Laboratory Studies and Support

1. Continued studies with a DNA amplification technique, the polymerase chain reaction, to rapidly detect HIV genetic sequences in chromosomal DNA.
2. Continued initial studies on new human herpes virus (HHV6) from cells of AIDS patients.
3. Continued laboratory surveillance for the introduction of new HIV variants into the United States. Intensified work continues to document the presence of HIV-2 infections in the United States.
4. Continued studies to increase understanding of the duration of HIV infection before the detection of antibody.
5. Continued studies to develop sensitive and specific diagnostic tests for antibodies to detect early infection.
6. Initiated or expanded studies of dual infections with HIV-1 and HIV-2 through Projet Retro-C.I. in Abidjan, Cote D'Ivoire, West Africa.
7. Provided consultation in Romania on pediatric AIDS, and provided consultation and logistical support in the design and establishment of a new field laboratory in Thailand.
8. Continued studies to better understand animal models of HIV and simian immunodeficiency viruses (SIV) to define the pathogenicity and significance of immune responses to these viruses.
9. Provided ongoing consultation and laboratory support to assist producers of HIV antibody tests, manufacturers of prophylactic and therapeutic agents, and other organizations in their continuing development of new diagnostics, treatments, and potential vaccines.
10. Continued to provide extensive support to AIDS epidemiology, surveillance, and research projects.
11. Enrolled over 1400 laboratories in the CDC voluntary AIDS Performance Evaluation Program.

C. Implementation of Prevention Strategies

1. Developed a cooperative agreement to directly support 98 minority and other community-based organizations (CBOs) in the metropolitan statistical areas with the highest number of reported AIDS cases. Sixty-six of these CBOs represent and serve racial and ethnic minority populations.

2. Supported initiatives in State and local health agencies to prevent HIV in racial and ethnic minority populations. More than 315 organizations received support through this funding mechanism.
3. Implemented a National and Regional Grant Program for Minority Organizations and awarded 32 grants for more than a total of \$6 million.
4. Provided financial and technical assistance to the United States Conference of Mayors for seed funding and technical assistance to minority CBOs in fiscal year 1990. In 1990, four one-year, non-renewable grants for a total of \$369,000 were awarded to CBOs serving persons infected with HIV. Moreover, eighteen new CBOs will receive 1990 funds for HIV prevention.
5. Provided support to fund health education/risk reduction; counseling, testing, referral, and partner notification (CTPRN); public information; and racial and ethnic minority initiatives in 65 States, territories, and cities.
6. Provided financial and technical assistance to support seven cooperative agreements with States, localities and other nonprofit entities to implement and evaluate approaches to preventing perinatal transmission of HIV infection.
7. Provided financial and technical assistance to six community-based demonstration projects to assess and validate intervention strategies for use in ongoing programs.
8. Provided technical and financial assistance, in collaboration with HRSA and the National Hemophilia Foundation, to support 18 hemophilia behavioral intervention projects to prevent sexual and perinatal transmission of HIV to persons with hemophilia and their sex partners.
9. Developed, in concert with HRSA, professional training programs for health care professionals to permit health care delivery systems to respond to the needs for information as well as technical services.
10. Continued interagency agreement with HRSA to support pilot programs for HIV prevention and treatment in community health centers. Data have been collected and are currently being analyzed. Results will be documented and used in 1991 by HRSA and CDC to help shape nationwide implementation of integrated HIV prevention and care services.
11. Began studies to evaluate the impact of HIV counseling and testing in drug treatment centers and STD clinics and to evaluate the effectiveness of counseling, testing, referral, and partner notification (CTPRN) in a variety of settings. Findings will be used to strengthen CTRPN efforts.

12. Integrated specialized counseling information and skills into ongoing public health training programs associated with the HIV epidemic, and developed and delivered specific educational and training seminars to respond to scientific breakthroughs.
13. Provided support to 23 national education and health organizations that work to increase the number of schools and youth serving agencies providing HIV education for youth. Many national organizations developed and disseminated materials to inform the Nation's educators about the need for HIV school health education and the role that educators, school superintendents, school boards, and others can play to support schools in their HIV education efforts.

For example, the National Association of State Boards of Education (NASBE) published Someone at School Has AIDS: A Guide to Developing Policies for Students and School Staff who are Infected with HIV. To develop the guide, NASBE convened experts in medicine, public health, education, and law. The guide recommends scientifically and legally based policy statements that State and local departments of education can use in developing policies for HIV-infected students and staff..

14. Provided support to State and local departments of education to help schools implement HIV education programs. In 1990, virtually every State department of education provided training programs to enable teachers and other professional staff to teach youth about HIV. For example, over 400 educators were trained at 9 training workshops conducted by the Washington State Department of Public Instruction. In addition, the Department provided HIV education training to 60 educators from youth correctional facilities, youth shelters, and group homes.
15. Expanded a materials development and dissemination system to identify, develop, and provide information about interventions that can be used to help school and college-aged populations avoid risks for HIV infection and other important health problems. These materials include curricula, films, videotapes, audio tapes, policies on health education, policies on disease and injury control, books, teacher training programs, materials for parents, brochures, etc. Over 600 abstracts describing these materials have been entered into a database for easy access by educators.
16. Provided support for training and demonstration centers to train school and community personnel to implement state-of-the-art interventions that can help young people avoid risks for HIV infection and other important health problems. Two centers provide training for State-based teams from across the Nation, while one center emphasizes training of city-based teams. Twelve smaller regional training centers train school and community personnel in their regions to implement comprehensive school health education curricula.

17. Expanded the surveillance system for assessing school-based HIV education programs so that funded State and local departments of education will be able to determine the number and percentage of: 1) schools that provide HIV education at each grade level; 2) students that receive HIV education at each grade level; and 3) schools that provide HIV education within comprehensive school health education programs. In addition, 35 State and 10 local departments of education conducted surveys to assess HIV-related knowledge and beliefs among samples of high school students in their jurisdictions. Finally, similar questions were used in a survey of a national sample of high school students in the United States to assess on a national level HIV-related knowledge and beliefs.
18. Continued development of an evaluation research system by offering two training conferences to help State and local Departments of Education evaluate and consequently improve their efforts to reduce risks for HIV infection and other health problems, to conduct research about the effectiveness of specific disease interventions, and to identify principal determinants of HIV-related and other health risk behaviors.
19. In 1990, published and disseminated 10 MMWR articles (in final and camera-ready form) containing guidelines and recommendations concerning the prevention and control of HIV infection.
20. Sponsored the second National Health Communications Conference on HIV and AIDS in February 1990, which brought together State AIDS Coordinators, public information officers, and media liaisons to improve State and local media outreach skills and strengthen the national health communications infrastructure.
21. Supplanted the Parents and Youth phase of the America Responds to AIDS campaign with phase V of the campaign designed to improve risk assessment capabilities of vulnerable populations.
22. Initiated collaborative relationships with approximately 25 percent of the State and local AIDS hotlines, giving them access to the National AIDS Hotline's Spanish language and hearing impaired services and to its information and referral resources.
23. Implemented recommendations contained in the National Academy of Science's report on Evaluating AIDS Prevention Programs in an effort to improve the effectiveness of CDC's health communications programs for HIV and AIDS.
24. Sponsored creation of an ad hoc task force of Federal health and commerce representatives and CDC grantees which is developing guidelines and strategies for worksite education, with an emphasis on small businesses (fewer than 100 employees).
25. Provided financial and technical assistance to KCET-TV in Los Angeles to develop its documentary on Hispanic women and AIDS. Through airings on national Public Broadcasting System stations

and the Spanish network, Univision, this program is estimated to have reached over 40 million Spanish-speaking viewers in this and 22 foreign countries.

26. Reviewed proposed scripts and suggested story line messages to television and film producers and writers which have contributed to the inclusion of HIV prevention messages in numerous television stories during TV's fall 1990 season.

CENTERS FOR DISEASE CONTROL

National Center for Health Statistics

HIV RELATED ACTIVITIESNational Health Interview Survey

A special 15-minute questionnaire on AIDS and HIV is administered to one adult respondent in each household as a component of the National Health Interview Survey (NHIS). The NHIS collects health data in about 50,000 households each year. About 800 HIV questionnaires are completed each week, and results are published in the Advance Data series, currently on a quarterly basis. This study was added to the NHIS in August 1987 and will continue with periodic modifications to the content. Information is obtained on knowledge about HIV transmission, HIV testing, assessment of risk and prevention of HIV.

National Mortality Data

Mortality data for HIV infection from the national vital statistics system (NVSS) are based on a new coding and classification system developed by the National Center for Health Statistics and the Center for Infectious Diseases - both of the Centers for Disease Control -- and implemented for deaths occurring in 1987. Beginning with deaths occurring in 1987, final mortality data for HIV infection are published annually in summary in the Monthly Vital Statistics Reports (MVSr) and subsequently in the Vital Statistics of the United States. More current provisional estimates of HIV-related and other cause-specific mortality are published monthly in the MVSr three to four months after the date of occurrence.

National Hospital Discharge Survey

The National Hospital Discharge Survey adopted the new International Classification of Diseases codes for HIV in October 1987. This continuous survey makes estimates of the number of hospital discharges, and related characteristics such as length of stay, from information abstracted from records in a sample of short-stay hospitals. Data on "AIDS-related" discharges are published in the Advance Data series.

National Mortality Followback Survey - 1986

The National Mortality Followback Survey is based on a one-percent sample (about 20,000 total deaths, including almost 300 HIV-related deaths) of 1986 death certificates with information about the decedent collected in a mail questionnaire. Information is obtained about socio-demographic characteristics, utilization of services during the last year of life and health behaviors. An Advance Data report entitled "Characteristics of Persons Dying from AIDS" was published in August 1989.

National Mortality Followback Survey - 1993

At least 2,000 AIDS deaths will be included in the 1993 survey of 20,000 deaths. The National Mortality Followback Survey (NMFS) sample is of U.S.

death certificates; data collection is from informants (usually close family members and hospitals where decedents were hospitalized in the last year of life.) Investigations will include the study of alternative family and institutional care strategies for AIDS victims; cost burdens of these care strategies; gaps in insurance coverage; AIDS and impairment of daily activities; and surgeries, procedures, and drugs used for AIDS victims in hospitals. These nationally-representative data will be instrumental for providing information on prevention of premature deaths from HIV, the use of social and community services and supports in the last year of life for those infected with HIV, and socioeconomic differentials in mortality.

National Survey of Family Growth - 1988

The National Survey of Family Growth is a periodic household interview survey of women of childbearing age designed to monitor changes in childbearing practices and to measure reproductive health. The 1988 survey of 8,450 women included questions on awareness of sexually transmitted diseases (including HIV), and changes in sexual behavior to avoid such diseases, as well as questions assessing the likelihood of getting HIV. This survey routinely collects data on sexual partner history. HIV-related data were published in 1990. In 1990 women interviewed in 1988 were reinterviewed by telephone to monitor changes in fertility, contraceptive practices, and knowledge and attitudes about sexually transmitted diseases, including HIV infection.

National Maternal and Infant Health Survey - 1988

The 1988 National Maternal and Infant Health Survey (NMIHS) is an indepth study of 10,000 live births, 6,000 infant deaths, and 4,000 late fetal deaths; one half of the NMIHS sample is black. After poststratification, the NMIHS will be weighted up to estimate AIDS/HIV testing and prevalence among mothers and infants for 3.9 million live births, 37,000 infant deaths, and 15,000 late fetal deaths. Hospitals and prenatal care providers are asked if the mothers and infants were tested for HIV, types and dates of tests, and ICD-9 medical coding. Up to two mailings and two reminder calls are made by the Bureau of the Census to obtain hospital and prenatal care provider response. Provisional data tapes have been released to 15 cosponsor agencies; public use tapes and reports will be available in August 1991.

NMIHS Longitudinal Followup - 1991

The 1991 Longitudinal Followup (LF) involves reinterviews with 12,000 mothers who were in the 1988 National Maternal and Infant Health Survey (NMIHS). The 10,000 LF mothers who had live births in 1988 will be asked if they had an HIV test, as well as several AIDS knowledge questions. The 10,000 pediatricians and 2,500 hospitals for their now 2 1/2-year old children will be asked if the infant has had an HIV test, date of test, and type of test. The 2,000 LF respondents who had infant deaths or late fetal deaths in 1988 will be asked if they have had an HIV test and several AIDS knowledge questions. LF data will be linked with NMIHS in order to create a pediatric HIV/AIDS data base. Data collection will occur in 1991; reports and public use tapes will be available in 1992.

National Health and Nutrition Examination Survey III - 1988-1994

The National Health and Nutrition Examination Survey III is collecting data through direct physical examinations of 30,000 persons during the period 1988 - 1994 in mobile examination centers. A sample of the blood drawn from adults will be blinded and anonymously tested for HIV status. Results from the first half of the sample will be available in 1992.

National Ambulatory Medical Care Survey - 1989

The National Ambulatory Medical Care Survey collects data about physician visits from a sample of physicians. The 1989 survey included questions on the data collection form about whether the patient was counseled about HIV and if an HIV test was performed.

National Household (HIV) Seroprevalence Survey

In mid-1988 a study was begun to determine the feasibility of a national household survey to measure HIV infection in the U.S. population. A pilot study of 300 households, conducted in Allegheny County, Pennsylvania, was completed in February of 1989 with a participation rate of approximately 80%. Based on procedures developed during the pilot, a second larger and more complex field test was conducted in Dallas County, Texas, in September-December 1989. From a sample of approximately 2,500 addresses, 1724 eligible persons were identified and 82% of those consented to participate by providing a blood specimen and completing a questionnaire on risk behavior. Among 18- to 54-year olds in Dallas County, the overall HIV seroprevalence estimate was 0.4%, indicating that approximately 4,000 persons in this population were HIV-infected. To evaluate the survey estimate, several model-based estimates were prepared for Dallas County using back-calculation, a statistical method which uses observed AIDS incidence and estimated AIDS incubation period. Although the survey estimate was adjusted for nonresponse bias, HIV seroprevalence estimates derived using back-calculation models all exceeded the household survey estimate. Based on responses to the questionnaire, an estimated 7.7% of males in Dallas County reported having had sex with another male since 1978, and 4.5% reported receptive anal intercourse. In addition, 4.0% of all household residents reported using intravenous drugs since 1978. Overall, 20.2% reported having engaged in one or more risk behaviors for HIV infection. Because prevalence estimates are available from current CDC HIV surveillance activities and considering the substantial level of resources required for a national survey, as well as the potential bias in its estimates, CDC has recommended that a national household survey to estimate HIV seroprevalence not proceed.

Methodological Research on Improving Survey Response to Sensitive HIV-related Topics

NCHS is expanding its cognitive research in questionnaire development in the area of HIV-related surveys to improve the reporting of sensitive, high risk behaviors in surveys. This effort is critical to measuring the patterns and distributions of high risk behaviors and in evaluating the impact of HIV education programs. Plans include developing an inventory of HIV-related questionnaires to increase the collaboration of HIV researchers and further enhance the comparability of surveys.

Alcohol, Drug Abuse, and Mental Health Administration

Acquired Immunodeficiency Syndrome (AIDS)

The Department of Health and Human Services has identified Acquired Immune Deficiency Syndrome (AIDS) as the foremost public health problem in the United States. As of October 1990, 152,126 cases of AIDS have been reported, with approximately one million Americans estimated to be seropositive for human immunodeficiency virus (HIV). An estimated 40,000 persons are becoming newly infected each year. In 1989, AIDS was the 11th leading cause of death in the United States. While there is no accurate estimate of the rate of HIV infection among teens, a recent survey of HIV seroprevalence on college campuses indicated that 1 in 500 students was infected.

National Institute of Mental Health

The significance of the interactions among neurologic, immune, and behavioral factors of HIV infection has only recently been recognized. It is now accepted that HIV enters the central nervous system (CNS) early in the course of the disease producing a range of nervous system impairments. In 25 percent of HIV patients, CNS impairment was the first symptom manifested, and in 9 percent it was the only clinical symptom occurring before confirmation of HIV seropositivity.

A large number of persons infected with HIV experience neurological, cognitive, and behavioral changes, and CNS impairment is common by the time HIV infection has advanced to AIDS. Up to 60 percent of persons with AIDS may eventually develop AIDS Dementia Complex (ADC). Primary dementia has become so closely associated with AIDS that the Centers for Disease Control now recommends HIV testing for people exhibiting dementia. Cognitive impairment is the most overt and disabling aspect of ADC, which can also include slowness in thought processes, limited attention span, memory impairment, altered consciousness, anxiety, mood changes, seizures, confusion, speech difficulties, motor abnormalities, and paralysis. The precise cause of the neuropathology in HIV infection remains unknown.

NIMH is committed to the development of behavioral strategies to prevent further spread of the disease through research on the determinants and antecedents of risk behaviors, the distributions and patterns of HIV-related risk behaviors, and the implementation and evaluation of prevention approaches. Counseling HIV-positive individuals is one strategy to produce behavior change that will reduce the further spread of HIV. Effective prevention strategies require the cooperation and support of infected persons and their integration into adaptive social support networks. Psychological distress and poor mental health functioning adversely affect both cooperation and social support. Learning of a positive test result may have profound

psychological effects on the individual, such as social withdrawal, paralyzing anxiety and depression. Also, there is a highly elevated risk of suicide in HIV positive individuals.

Accomplishments

Neuropsychological Assessment

NIMH has completed development of a series of tests to assess neuro-psychological functioning in HIV-infected adults. Preliminary research has indicated that asymptomatic HIV-positive individuals show statistically significant memory deficits as well as a slowing in the processing of specific types of information compared to HIV-negative individuals. Intramural scientists are investigating possible mechanisms underlying the cognitive and other neuropsychiatric deficits seen in AIDS patients.

These tests are being disseminated widely through publication in a major professional journal, and NIMH will encourage researchers with Federally-funded projects to utilize these test so that results can be compared across research sites. Efforts to relate information obtained on neuro-psychological assessment in asymptomatic HIV infected individuals to actual performance will be undertaken. The ability to compare data across a series of research studies and populations will provide a larger database for policy decisions, guidance on meeting the health care needs of individuals with neurological impairment, and methods for early detection of the disease.

New Findings in the Neuroscience of AIDS

NIMH intramural scientists are collaborating with the FDA to investigate the interaction between HIV-1 and cultured brain neurons. When the neurons are exposed to HIV-1, a progressive disruption of the network and destruction of cells occurs; additional testing revealed that only neurons, not other brain cells, are killed. Viral proteins and HIV-1-specific DNA and RNA are detected in the neurons. This is the first evidence that the neuron is a direct target for HIV-1. In addition, the group has preliminary results showing that three protein species isolated from various plants have anti-HIV-1 activity. The team plans to: 1) describe the cell-surface receptor systems utilized by HIV-1 for entry; 2) investigate the sequence of events leading to the death of neurons after HIV-1 infections; and 3) develop modalities that would reduce or prevent the damaging effects of HIV-1 on neurons and lymphocyte systems.

Quinolinic Acid Implicated in AIDS Dementia

NIMH Intramural scientists are studying quinolinic acid, a metabolite of the naturally occurring brain amino acid tryptophan, as a possible cause and marker of neurological damage in HIV-infected individuals. Low levels of quinolinic acid are normally present in the brain, but high concentrations can cause convulsions and damage to brain tissue. NIMH researchers have found that levels in HIV-infected people remain elevated for

extended periods, and they decrease markedly when patients receive zidovudine (AZT). In patients with clinically overt ADC, quinolinic acid levels are elevated over 20-fold, and levels are associated with the progressive severity of cognitive and motor dysfunction. Significantly, in monkeys with simian immunodeficiency virus infection, which resembles HIV infection, the key enzyme responsible for the production of quinolinic acid is elevated up to 6-fold. It appears that quinolinic acid may contribute to AIDS dementia by destroying brain tissue or by disrupting normal brain functions.

Brain Immune Interaction

Immune function can be influenced by neurological and psychological factors because it is intimately connected to the brain which controls both the CNS and immune systems. HIV affects the brain, the nervous system, and the immune system, leading to progressive immune system failure, CNS degeneration, and ADC. Impairment of the usual interaction between the CNS and the immune system could affect susceptibility to HIV infection, as well as the progression of the disease and development of neurological symptoms. Researchers are studying what makes individuals susceptible to the virus and what factors influence the course of infection.

One factor receiving attention is stress. Recent findings suggest that the level of receptors for interleukin-2 (IL-2), and the level of messenger RNA, (which provides the blueprint for building the receptors) are significantly decreased in medical students experiencing stress during examination periods. Physiological changes associated with psychological stress may have an effect at the level of gene expression by reducing the amount of genetic material available to guide the synthesis of this important immune system protein.

A promising experimental treatment for AIDS destroys the immune system's T cells by X-ray irradiation and replaces the immune system by transplanting healthy bone marrow in conjunction with AZT therapy. Preliminary results of studies by intramural scientists have demonstrated the effectiveness of an alternative method that destroys infected T cells with protein toxins. This eliminates the need for bone marrow transplant with the attendant side effects.

Current Activities

NIMH supports a broad, balanced program of AIDS mental health research, research training, and health care worker training. The PHS Strategic Plan and the Charlottesville Report both highlight the need for research to fill gaps in knowledge in neurosciences, brain-immune interactions, prevention, and behavior change. The Institute of Medicine (IOM) report on Confronting AIDS: Update 1988 recommends long-term, comprehensive programs of research in the biomedical and social sciences intended to prevent HIV infection and to treat the consequences

of the disease. In AIDS: Sexual Behavior and Intravenous Drug Use (1989) and AIDS: The Second Decade (1990), the National Research Council of the National Academy of Sciences recommended a series of activities to increase and improve programs of basic social and behavioral research related to HIV infection and AIDS.

Neuroscience of AIDS

The newest AIDS Research Center on Molecular and Cellular Mechanisms of AIDS Dementia at the Research Institute of Scripps Clinic in La Jolla, California will investigate the molecular and cellular mechanisms underlying ADC through a highly focused comparative evaluation of brain pathophysiology in AIDS patients with that found in three animal models. The Center will correlate virus-dependent changes in immune system and nervous system function with the clinical profile of AIDS. These multidisciplinary studies will define the biological actions of persistent virus infections of the brain, the profiles of cell to cell signals activated by these infections, and the nature of the effects of these signals on neuron function.

Several reports have demonstrated the value of the laboratory rabbit as a model for HIV-1 infection. This work is being pursued by NIMH intramural researchers, Drs. Henrietta Kulaga and Richard Jed Wyatt, in collaboration with the National Institute of Allergy and Infectious Disease. Injection of rabbits with HIV-1 infected cells was shown to cause infection as measured by seropositivity and by detection of HIV virus in organs. These animals also showed diminished immune responses. Infection of rabbits with HIV-1 provides a practical animal model for studying the neuropathology of AIDS. This technique may also be used for hard to diagnose patients, especially in cases where seropositivity cannot be satisfactorily determined by traditional methods, e.g., in babies who may test positive but are not infected. Furthermore, this system offers an excellent opportunity to test putative anti-AIDS vaccines and drugs.

Peptide T Trials

Peptide T, a compound developed by NIMH intramural scientists, has been associated with potentially beneficial clinical effects, particularly related to improved neurocognitive functioning and mood. In two Phase I clinical trials to test the safety of Peptide T, no toxic effects were identified. A Phase I/B study of HIV infected injection drug users stabilized on AZT has just been initiated in collaboration with Yale University. This protocol will assess the effects of Peptide T on immunologic, virologic, and cognitive-neuromotor measures. This is the first opportunity to study the effects of Peptide T in combination with AZT and to assess its potential in an understudied population of HIV patients. At the University of Southern California, a Phase II trial is currently being conducted that will be the first placebo-controlled, double-blind study to evaluate the effects of Peptide T in HIV positive individuals with neuropsychological

symptoms. This study will also test Peptide T in combination with AZT.

Psychological Effects of AIDS

Preliminary data from ongoing intramural studies indicate that improvement as a result of treatment in cognition is not connected to an improvement in mood. These data indicate that although antiviral AZT or alpha-interferon treatment ameliorated HIV effects on cognition it had no measurable affect on mood. More severe mood alterations may affect performance on neuropsychological tests, indicating a need for more sensitive measures of cognitive processing in HIV disease.

Behavior Change/Prevention

Research on behavior change and prevention is a major focus of the NIMH AIDS Program. Priorities include identification of determinants of high-risk sexual and drug using behaviors; determinants of maintaining low-risk behaviors, especially for hard-to-reach populations; the social contexts in which risk-taking behaviors occur; the impact of affective states (e.g., depression, anxiety, social isolation) on risk behavior; the effects of cognitive impairment on adherence to risk reduction guidelines; and the development of more accurate methods to assess behavioral determinants, patterns of risk behaviors, and behavior change.

A series of NIMH-supported research projects indicate that, although some groups at high risk for HIV infection have changed behavior, a significant proportion have continued to engage in behaviors that place them at high risk for AIDS. Emerging data also point to the "relapse" phenomenon, in which individuals return over time to earlier levels of high risk behaviors. Development and testing of effective relapse prevention strategies are important priorities. A series of NIMH-supported studies indicate that individual and small group interventions with at-risk individuals result in reducing HIV related risk behaviors. Strategies include cognitive behavior therapy, assertiveness training, skills training, and stress reduction.

An intervention study has revealed an innovative strategy for reducing high-risk sexual behavior for HIV infection among gay men in small communities. After a community-level prevention program, investigators found a 22-36 percent reduction in these behaviors. The experimental program trained popular opinion leaders to promote positive health changes within their social group. Training peer leaders in AIDS education may result in significant changes at less cost than other approaches, especially in small communities with a stable population where formal health education programs are rare.

A study of more than 2,000 Houston area high school students is exploring the amount of knowledge students actually have about AIDS, its dangers and its transmission. Investigators are studying the degree to which drugs, alcohol use and emotions

influence risky sexual practices among teenagers; whether gender differences relate to being at risk for AIDS; the psychological-social profile of students who are at risk for contracting AIDS; and specific risk factors for minority adolescents who are at risk for contracting AIDS.

The Center for AIDS Prevention Studies in San Francisco is a confederation involving the University of California at San Francisco; the University of California at Berkeley; the Bayview Hunters Point Foundation, a community-based health and mental health setting with Black and Hispanic investigators; the San Francisco Department of Public Health; and San Francisco General Hospital. In addition to projects that address risk behaviors and the development of effective culture-specific prevention strategies for a number of at-risk populations, the Center is supporting 25 innovative pilot studies to determine the most promising areas for future research investment.

A major initiative in FY 1990 was a prevention study designed to: 1) develop behavioral intervention strategies for groups of individuals at high risk for HIV infection not reached effectively by existing efforts, 2) assess existing interventions and improve educational and mass media strategies that have shown some effectiveness, and 3) develop a comprehensive intervention program to promote behavior change that will prevent the further spread of HIV. These multi-site, multi-population, controlled trials are designed to establish causal links between behavioral interventions and behavior change. This study will include special emphasis on producing the desired prevention outcomes in hard-to-reach, underserved populations including ethnic minority groups.

Adolescents and Young Adults

Knowledge of HIV transmission alone is a very poor predictor of behavior change in adolescents. Intervention studies in schools have demonstrated increased knowledge of HIV and increased tolerance for persons with AIDS among some junior high school students, but HIV risk behaviors have not been reduced. Additional concern arises from emerging data from a series of studies that point to the "relapse" phenomenon, in which individuals return over time to earlier levels of high risk behaviors. Since adolescence is often a period of initiation into sexual and drug use behaviors that put youths at risk for HIV, prevention of infection is critical for this age group.

For adolescents, a major priority is development of behavioral strategies to prevent transmission of HIV. Research is supported on determinants, antecedents, distributions and patterns of HIV-related risk behaviors among different groups of adolescents, and implementation and evaluation of prevention approaches. Research seeks to identify relative efficacy of school-level educational strategies to prevent or reduce risk for HIV infection in adolescents. Little is known about rates of HIV infection and

prevention strategies in special groups, including adolescent runaways, emotionally disturbed adolescents, minority adolescents living in inner cities where the prevalence of HIV infection is high, homosexual adolescents and young men, and young people using drugs and alcohol during sexual activity. Effective, culture-specific behavioral interventions need to be developed to reduce HIV-related risk behaviors for adolescents, many of whom are hard to reach with traditional AIDS prevention programs.

In one study, a videotape program for family and home use is being developed that instructs parents and adolescents about causes and prevention of AIDS. Problem-solving and role playing are used to provide adolescents with skills necessary to avoid high risk sexual and drug situations. Prevention studies are currently underway to evaluate strategies for increasing condom use among sexually active adolescents. Populations under study range from a group of Haitian youth in Miami to gay and heterosexual teens in San Francisco. Disinhibiting effects of crack and alcohol as contributing factors in high risk sexual behavior among adolescents are also being studied. In addition, the effectiveness of teacher- vs peer-delivered interventions are being evaluated. Results from these studies should contribute to understanding the components of successful interventions that can be adopted by schools and social service programs.

An AIDS prevention study is developing and evaluating an intervention aimed at reducing high-risk sexual and drug-using behavior among runaway and gay youth in New York City. The target population includes 900 male and female adolescents between the ages of 12 and 17 who seek services at shelters for runaways or at an agency serving gay and lesbian youth. A study of HIV in street youth integrates multi-method preventive intervention approaches at two sites (the urban slums of Belo Horizonte, Brazil and urban Baltimore, Maryland). These sites present a rare opportunity due to high incidence of HIV infection among children and adolescents. The Brazilian governmental, university, health, and youth care organizations have invited the research team to collaborate in longitudinal assessment of risk factors for HIV seropositivity, descriptive behavioral studies, and controlled prevention research in a concerted effort to help several million street youth.

Mental Health Services Research

For the mental health community, the increased incidence of HIV presents special challenges. The mental health system must respond to an even greater demand for services by a new population of patients: those who suffer from mental illness and become infected with HIV, as well as those in whom the virus triggers emotional or mental disorders. A study of New York City psychiatric inpatients has found a high rate of HIV infection (7.1 percent for 350 consecutive admissions of inpatients ranging in age from 18 to 55 years. By comparison, infection rates of 1-6 percent were found among patients admitted for non-HIV illness in three New York City general hospitals regularly surveyed by

the Centers for Disease Control. Approximately 25 percent of the HIV-positive psychiatric patients in this study were female. These results in a private psychiatric hospital indicate that individuals with severe mental disorders constitute a major high risk group for HIV infection.

To address the complex issues surrounding HIV infection and pre-existing mental illness, NIMH sponsored a meeting on HIV infection, AIDS, and mental health services attended by eleven mental health organizations. Topics included testing, confidentiality, patient management and patient education. Other issues of concern were management of violent or sexual behaviors and the lack of access to services for patients with mental illness. Furthermore, there are problems unique to mental illness, such as interactions between drugs used to treat HIV and psychotropic medications.

Research Training

In FY 1990, NIMH sponsored a Research Training Seminar/Workshop for Early Career Minority Investigators. The objective of this venture is to increase the number of minority researchers who serve as principal investigators on HIV-related mental health research. The effort has also included a technical assistance workshop to provide orientation to the grant application and review process and consultation in the theoretical and applied aspects of minority mental health research.

Health Care Worker Training Program

Since FY 1986, NIMH has supported a program to develop model curricula and test methods of providing education and training for health care providers in the neuropsychiatric and psychosocial aspects of HIV infection. In FY 1990, the NIMH Health Care Worker Program continued support for grants to integrate AIDS mental health training into health care AIDS training provided through the HRSA Education and Training Center (ETC) program. Evaluation activities continued to assess educational strategies and their outcomes. A recent NIMH publication, When Someone Close Has AIDS, and the newly-published Spanish version, will be distributed widely to health care workers.

For many health care providers, HIV infection is the first experience with otherwise healthy young people dying. The serious mental disorders that are related to HIV infection, such as dementia and major depression, are challenging our health care provider educational system in new and complex ways. The task has been especially challenging since HIV has disproportionately affected minority populations and stigmatized populations such as gay men and injection drug users.

The NIMH program has placed special emphasis on reaching health care providers who serve minorities, women, and children. New efforts in the area of training of health care workers and providers will emphasize training in pre- and post-HIV antibody

test counseling. With the recommendation of prophylactic treatments for asymptomatic HIV positive individuals, large increases are expected in the numbers of high risk individuals who will undergo HIV antibody testing. Skilled pre- and post-test counseling efforts may play a key role in minimizing negative psychological and psychiatric outcomes for persons with HIV infection and in facilitating behavior change necessary to prevent the further spread of HIV.

Evaluation activities have been designed to assess the impact of the NIMH AIDS mental health care provider training efforts. Based on the findings, new initiatives may be developed to address potential gaps in the Institute's AIDS program training efforts. Efforts will be undertaken to enhance the national capacity to address special mental health training needs of the core mental health disciplines.

The Future

New Animal Models

Existing models have limited utility for the study of the neuropathological effects of HIV. The SIV simian model, which has been in use the longest and resembles human HIV infection, has not yet been evaluated for behavioral and neurological abnormalities present in ADC in humans. NIMH is planning a series of initiatives to encourage the development of animal models of HIV infection to study CNS impairment in human ADC. In addition, since new therapeutic developments have prolonged the life span of HIV-infected individuals and shown efficacy in slowing or even reversing the neuropathologic effect of the virus, an appropriate animal model could be useful in evaluating the mechanisms of action of experimental drugs specifically designed to reverse neuropsychological symptoms, and in examining their interaction with antiretroviral drugs.

Medication Development

NIMH is continuing a program to develop psychotherapeutic agents from natural sources that may have potential for treatment of HIV infection in the brain. NIMH will receive plant and animal samples with the potential for yielding such drugs from the National Cancer Institute's Natural Products Screening Program. NIMH is supporting the study of the prevention of high-risk behaviors through both behavioral and pharmacologic intervention. These efforts will be expanded to include further research on the effects of psychopharmacologic agents used in the treatment of psychological sequelae of HIV infection and their interaction with anti-HIV drugs. This research will provide a better understanding of the potential effects of these medications on risk-taking behavior, which is critical in the development of effective AIDS prevention strategies.

Prevention Research

AIDS prevention studies will be extended further into hard-to-reach populations that have been understudied in the HIV epidemic (e.g., Hispanic females, minority gay and bisexual men, and institutional populations such as prisoners, hospitalized mental patients, and adolescents in residential treatment facilities) and to different geographical sites. Special efforts will continue to test culture-specific prevention approaches in ethnic and racial minority groups that have been disproportionately represented among U.S. AIDS cases.

One focus of behavioral research will be adolescents at risk. Age-specific data is necessary for development of effective prevention programs and to evaluate relative efficacy of elementary, junior and senior high school-level educational strategies. Serious gaps in knowledge exist concerning determinants of AIDS risk behavior and behavior change in children and adolescents. Future research will focus on the following areas: identification of determinants of high-risk behavior and determinants of maintaining low-risk behavior; social contexts in which risk-taking behavior occurs; impact of affective states (e.g., depression, anxiety, social isolation) on risk behavior; effects of cognitive impairment on adherence to risk reduction guidelines; and development of more accurate methods of assessment.

Mental Health Services Research

Priorities include research focused on HIV infection among the severely mentally ill, and mental health services for HIV-infected individuals who develop HIV-related mental disorders. HIV infection among the homeless mentally ill is also a priority topic. Particular emphasis will continue to be placed on research on the financing and reimbursement of mental health services for persons with HIV infection.

In another area of services research, NIMH plans to increase research efforts focused on families. There is a need to identify mental health effects of HIV infection and AIDS on families, and to catalog coping mechanisms used by families living with HIV infection. Evaluation of mental health services and supportive systems of care, designed to maximize functioning and minimize mental health problems in families with HIV infection, is required.

National Institute on Drug Abuse

Drug abuse is the second leading risk factor for acquiring HIV in adults; it is the primary risk factor for infants. HIV is primarily spread among injection drug users (IDUs) by needle sharing, a common practice that serves both practical and social functions. HIV infection, however, is also spread sexually between IDUs and their sex partners (non-drug using as well as drug using), and perinatally from infected mothers to their children. In 1990, approximately one-third of all reported AIDS cases were associated with injection drug abuse; minorities are over represented among such cases.

Injection drug use is directly related to HIV infection through blood contamination of shared equipment. In addition, there is also evidence that both injection and non-injection drug use is correlated with sexual activities that place persons at risk for HIV infection. The processes by which drug use mediates risky behaviors (e.g., disinhibition, uncommon behavior) are currently under investigation. For instance, there is considerable interest in the impact of the use of crack cocaine on sexual promiscuity and HIV infection. Reflecting this importance, NIDA continues to fund a wide range of AIDS research, spanning such areas as epidemiology and natural history, basic and clinical research, mathematical modeling, treatment improvement, outreach, education, and prevention/intervention.

Epidemiology and Natural History

Data from the Seroprevalence Monitoring System, a point-prevalence study of IDUs newly admitted to methadone treatment over the past three years, suggest that levels of HIV infection in this population have been fairly stable. Of seven cities studied, significant increases in HIV seropositivity levels were found in only one city, Chicago. Nonetheless, recent treatment admissions are still reporting high levels of HIV risk-behaviors. Comparisons of recent admissions with those admitted earlier indicate that reductions in risk-behaviors have been minimal. Since the majority of subjects reported having had one or more drug using sexual partner in the previous five years, there is considerable potential for HIV transmission via sexual contact as well as through needle sharing. These study findings indicate that current HIV prevention efforts targeted toward IVUs are inadequate. Thus, the need for prevention initiatives continues to be great.

Among IDUs living in areas with low prevalence of HIV infection, needle sharing by heterosexual IDUs with homosexual and bisexual IDUs was found to be an important means by which HIV is introduced into the heterosexual IDU community. IDUs who reported sharing needles with homosexual or bisexual men were more likely to be infected than those who did not. Because HIV appears to be especially concentrated among homosexual and

bisexual IDUs in areas of overall low prevalence, special prevention initiatives that target these IDUs are needed.

Research from the University of California at San Francisco indicates a flattened HIV-1 seroprevalence curve from 1987 through 1989. This leveling of HIV-1 seroprevalence coincided with self-reported reductions in key risk behaviors following an aggressive prevention campaign directed towards IDUs in mid 1986. A study to assess the seroprevalence, determinants of seroconversion, and factors related to disease development in steady heterosexual partners of HIV infected individuals is being initiated. Total enrollment is 124 partners and 59 index patients with HIV infection; 91 percent of partners are female and 73 percent of patients have acquired HIV infection through injection drug use. Overall, 45 percent of partners tested positive for HIV antibody. No significant association has been shown between antibodies for other infectious diseases such as cytomegalovirus and hepatitis B, and HIV serostatus. Eighty-three percent of seropositive partners have had at least one positive culture for HIV. Interestingly, seronegative partners show greater immunologic reactivity to HIV derived proteins than normal controls or seropositives. Subjects will be retested at intervals and the overall number of patients will be increased to explore the hypothesis that these responses may reflect either early infection or, conversely, immunity to infection. Preliminary data suggest that non-injection drug use (i.e. crack or alcohol) may be more important in predicting serostatus in partners of HIV infected patients than venereal infection.

Since needle sharing is the most common means of spread of HIV among drug abusers, a complete understanding of needle use behaviors is critical to the development of successful intervention strategies. An intramural study conducted in five sentinel cities was designed to obtain quantitative, reproducible measures of needle sharing behavior. With careful definition of needle sharing, it was possible to get consistent answers about this behavior from IDUs entering treatment. Preliminary results indicate important differences in needle sharing rates by demographic and drug using characteristics. Additional analyses are required, however, to determine which differences are attributable to differences among cities in needle availability and prevention and outreach efforts.

The overall prevalence of needle sharing was 64 percent with the proportion varying widely from a low of 45 percent to a high of 95 percent. Rates of sharing varied by gender, age, and ethnicity. A higher proportion of female IDUs shared injection equipment and three-quarters of IDUs under the age of 30 shared needles. Black respondents had the lowest rate of needle sharing, 52 percent compared with 76 percent of whites and 73 percent of Hispanics. Sharing was also more prevalent among frequent injectors. Common reasons given for sharing of needles were that needles and syringes were expensive, scarce, and because of personal habit. The prevalence of needle sharing was

slightly higher among persons who had received previous drug abuse treatment, and the behavior was not affected by previous AIDS counseling. These data indicate that renewed efforts for the development of more effective prevention strategies for the reduction of high risk behaviors among IDUs are quite urgent.

Comprehensive mathematical modeling of the AIDS epidemic is constantly refined and updated to incorporate changes due to new treatments or behavioral changes within risk groups. Using regional data, these models are tested against the consistency of assumptions about risk group sizes, incubation, infectivity, contact rates, and the impact of treatment or policy changes on the epidemic. As part of a large-scale, multi-site mathematical modeling grant, it has been reported that the presence of clandestine cohorts (unidentified at-risk persons) can result in seriously deflated standard errors in analyses; these errors may not be reliably reproducible. Statistical techniques for determining the extent of this deflation and, if necessary, correcting for it have been proposed.

Basic Research

Cognitive, neuropsychological and neuropsychiatric problems have been identified in some studies as possible early manifestations of HIV disease, and the role illicit drug use may play in neurologic disease is under investigation. A NIDA investigator has been studying the replication of wild type HIV-1 in CNS tissue culture. How the virus which normally infects specific lymphocytes (white blood cells with CD4 cell surface receptors) infects CNS tissue (not generally considered to express CD4 receptors) has been a matter of much speculation. Work completed thus far has shown that specific neurotropic variants of HIV-1 mediate neurologic pathology; methodological progress in cell explant culturing and identification of infected cells in culture; application of these improved methods to demonstrate the presence of HIV-1 in the kidney and bone marrow of patients with AIDS and to identify subpopulations of the many different cell types that harbor HIV-1. This group has also demonstrated that the infection of neuroblastoma cells in culture is, after all, mediated through the CD4 receptor. Continuing studies are examining the infection of neural tissue by HIV-1 by correlating the cell type infected with specific infecting agents, i.e., different strains of HIV-1, and whole virus versus viral fragments. Also, the effects of exposure to drugs of abuse on these processes will be investigated.

A NIDA grantee has released preliminary data on the first three years of a study concerning the neuropsychiatric consequences of HIV infection in 107 homosexual men and 132 heterosexual former injection drug abusers. Preliminary data analysis of the first 53 seropositive and the first 37 seronegative homosexual men showed that a combination of specific areas of neuropsychological dysfunction, increased conduction time, the presence of p24 HIV

antigen, elevated beta2, and reduced CD4 count may be predictive of the development of more severe cognitive impairment.

By extrapolating basic results to clinical application, this group of researchers has developed a Neuropsychiatric AIDS Checklist (NAC) which is a self report instrument that: (1) shows group differences between seropositives and seronegatives for both gay and IDU groups; (2) correlates with beta2, CD4 counts, and p24 antigen; and (3) shows a significant relationship with neuropsychological measures. This instrument may be a practical and efficient way of identifying those at risk for developing HIV associated cognitive impairment. Another instrument, the Neuropsychiatric Aids Rating Scale has been developed as a tool to assess the severity of symptoms due to AIDS Dementia Complex and has been found to predict management and residential placement problems in these patients.

Infectious Disease Associated with AIDS

Infectious diseases are commonly diagnosed and reported among drug abusers. Data from NIDA surveys of emergency room and medical examiner offices and CDC surveys for hepatitis, syphilis, tuberculosis and AIDS suggest that medical complications of drug abuse in the U.S. are increasing. AIDS causes such a drastic depletion of the body's natural defenses that individuals with HIV infection are plagued, often, with recurring opportunistic infections (infections that would not be a problem for healthy individuals). Some of the diseases acquired by AIDS patients are contagious to even relatively healthy others. Venereal diseases such as syphilis, and gonorrhea, and other diseases such as tuberculosis (TB) pose hazards to non-HIV infected persons as well as AIDS patients.

The incidence of tuberculosis decreased in the U.S. every year from the beginning of reporting in 1953 to 1985. In 1986, the incidence of TB increased for the first time. This increase seems to be related to HIV infection. HIV infected persons may also develop active TB at a much higher rate than non-HIV infected persons. Bacterial infection of blood and bacterial infections associated with the heart are common occurrences among IDUs. NIDA is sponsoring research to elucidate the role of HIV infection in infectious disease among drug abusers.

One investigator is examining the relationship between HIV infection and the occurrence and severity of bacterial endocarditis and other bacteremias in IDUs. Thus far the study has identified 134 bacteremias in 128 individuals with histories of injection drug abuse. Fifty-two individuals agreed to HIV testing and participation in the study. Results indicate a significantly higher percentage of HIV seropositives among the bacteremic cases vs controls (85 percent and 46 percent respectively). Also a trend towards more deaths from the infections and more recurrent infections among the seropositives (20 percent versus 12 percent) was observed. These results

support the inclusion of serious bacterial infections as part of the spectrum of pre-AIDS HIV related disorders and argue for vigorous prophylactic and treatment interventions among those at risk for HIV.

Prevention

In 1987, the National Institute on Drug Abuse (NIDA) initiated the National AIDS Demonstration Research (NADR) projects to study and change the high-risk behaviors of both IDUs who were not enrolled in drug treatment and their sex partners. The goal of these projects is to eliminate or reduce the likelihood of HIV transmission from these two high-risk groups. As of July 1, 1990, the projects included 40,000 IDUs and their sex partners in 41 community-based programs at 63 sites.

Preliminary data based on follow-up interviews of 1,584 primarily black male IDUs have been reported. Results were variable from community to community. Fourteen to 35 percent of IDUs participating in the first follow-up interview chose to enter a drug-treatment program during the approximately 6 months after enrollment in the demonstration project. Forty-nine to 75 percent reported stopping or decreasing their frequency of drug injection during the approximately 6 months between the initial intervention and the follow-up interview--including 16-47 percent who reported stopping all use of injected drugs.

The percentage of IDUs who reported not sharing drug-injection equipment with friends increased in the approximately 6 months between initial and follow-up interviews, as did the percentage of IDUs who reported not borrowing previously used drug-injection equipment. Thirty-four to 59 percent of IDUs reported decreased sharing of drug-injection equipment; 22-37 percent of IDUs reported decreased borrowing of drug-injection equipment. Of those who continued to inject drugs at follow-up, except for those who reported always using new needles, 20-39 percent of IDUs reported increased use of bleach for cleaning drug-injection equipment. Eleven to 43 percent of IDUs reported consistent use of bleach.

These preliminary results, which show an overall reduction in high-risk behaviors of IDUs, suggest that participation in outreach and intervention programs can influence entry into drug-treatment programs and can reduce drug-injection behaviors associated with increased risk for HIV transmission. If results from the remaining unanalyzed data prove to be consistent with these preliminary results, this approach could have considerable impact if implemented nationwide.

In general, prevention outcomes for women have been less favorable than for men. What is clear is that women's responses to preventive interventions is greatly affected by their cultural and risk-taking orientations, socio-economic status, and role and sense of power (both real and perceived) in decision making

around sexual and drug use behaviors. Women also encounter special barriers, such as pregnancy, child care needs, and greater economic deprivation, to entering drug treatment services and are, therefore, underrepresented in drug treatment programs.

Early on in the NADR project, it became obvious that these projects were having difficulty reaching and recruiting females even though there was no difficulty in reaching and recruiting males. The non-drug using female partners of IDUs have been a particularly hidden population; some do not know about or acknowledge their partner's use and thus may not realize that they, too, are at risk. In order to reach women, special strategies, including reaching far beyond traditional points of access were especially critical. Special technical assistance and training efforts were needed to develop a model outreach/intervention program and training curricula for staff working with women at risk.

Technology Transfer

A major aspect of NIDA's mission is to make available to the general and professional public, results obtained from NIDA-supported research. NIDA is dedicated to this mission and is sponsoring a number of ongoing projects.

In 1988, NIDA began a 3-year contract covering a variety of activities to increase awareness and stimulate the development of community education on the relationship of drug use and AIDS. The objective of this project is to provide an adequate and stable level of assistance and guidance to enable communities to establish and maintain their own educational programs. Technical assistance and support are provided to coalitions of programs at the state, local, and regional levels and also to national minority organizations. Training workshops and educational seminars on how to develop communications regarding the drug abuse-AIDS connection were conducted in 14 cities in 1990; workshops have been conducted in 35 cities since 1987.

NIDA now provides training in 17 HIV-related areas for substance abuse practitioners who are currently working in drug treatment programs. These training courses, which have been developed over the past 3 years, cover such areas as antibody test counseling, risk reduction counseling, working with women and minorities, and administrative issues. Five hundred administrators of drug treatment programs have been trained thus far.

NIDA has also asked the States to develop a State AIDS Training Plan, and has been working with them to help build their AIDS training capabilities by instructing State trainers and certifying them to deliver the NIDA AIDS courses. Individuals certified through this program have trained nearly 20,000 workers. Two hundred and fifty State and local agencies have received technical assistance on training and policy issues.

NIDA has also developed a series of prevention training efforts targeted to special populations, including high-risk adolescents, Hispanic women, and African Americans. The training includes workshops and comprehensive programs of education and skills building. It is estimated that by the end of 1990 over 11,000 treatment counselors and service providers will have been trained in at least one comprehensive HIV prevention counseling course and up to two advanced courses.

In July 1990, NIDA and the Advertising Council launched a new mass media campaign aimed at preventing drug abuse and AIDS among teenagers. The campaign, "AIDS: Another Way Drugs Can Kill," consists of three television spots, three radio public service announcements, a 60-second movie trailer, and print ads and posters. To help ensure that the ads will appeal to teens, the public service announcements for television were filmed as mini-movies by Oscar-winning director Martin Scorsese and narrated by director Spike Lee. The television spots were distributed to all network and local stations in the country as well as all cable television networks, including those targeting Black and Hispanic audiences. The radio public service announcements were issued to network and local stations throughout the country who cater to teen listeners. Print ads were distributed to all U.S. daily papers and magazines that target adolescents as well as consumer magazines and outdoor advertisers.

Collaboration with the Entertainment Community on AIDS and Drug Abuse: The media has tremendous influence on American viewers. In recognition of this unique responsibility, the Entertainment Industries Council, Inc. (EIC) continued its collaboration with NIDA to: (1) increase the awareness of industry personnel on AIDS and drug use and (2) encourage writers, directors, and producers to develop radio and television programming on AIDS and drug use issues. Activities included sharing messages on drugs and AIDS with film, broadcasting, and recording organizations for possible inclusion in their shows. For example, EIC and NIDA negotiated with a national foundation to collaborate on the second Hispanic song writing contest to promote public education on IV drug use and AIDS.

Drug Abuse Information and Referral Line (1-800-662-HELP): Operating since April 1986, the hotline answers calls 7 days a week. In 1990, more than 61,000 callers received referrals to drug abuse treatment as well as information on cocaine, other drugs, and AIDS. Staff also have been trained to talk about AIDS to callers who are injection drug users. This cooperative working relationship continued in 1990 between the NIDA hotline and the CDC-sponsored AIDS information line.

National Institute on Alcohol Abuse and Alcoholism

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) supports both extramural and intramural research on AIDS-related issues as well as research dissemination to alcoholism treatment providers.

Extramural Research

The goal of the AIDS-related research program supported by NIAAA is to stimulate multidisciplinary basic and applied studies on the role of alcohol consumption as a cofactor in HIV infection by 1) investigating the extent to which alcohol-induced suppression of the immune system contributes to susceptibility to viral infections; and 2) studying the association between alcohol consumption and high risk sexual behavior.

Research data indicate the dual nature of the relation between alcohol and AIDS. On the psychosocial level, alcohol consumption can result in the disinhibition of behaviors that facilitate exposure to HIV infection, including high risk sexual behavior. On the biological level, alcohol can cause various alterations of the immune system that may compromise host defence against HIV. These NIAAA-supported programs are discussed below.

Alcohol Use Compromises the Immune System and the Ability to Combat Infection: NIAAA-supported projects include a number of individual research grants, an alcohol research center grant and a research training grant, targeted in particular to those components of the immune system that can play a role in facilitating HIV infection or its progression to AIDS. These projects cover a wide range of basic and clinical immunological research.

Murine AIDS Model: Progress has been achieved in the study of the immunological profile of the murine AIDS infection. It has been shown that following infection, general proliferative capacity of the lymphocytes is rapidly inhibited. At the same time a subpopulation of the lymphocytes appeared activated after infection, which may play a role in the initiation of lymphadenopathy during murine AIDS infection. This model is quite significant in understanding how the virus attacks the immune system and, more importantly, in testing the efficacy of treatment modalities.

Alcohol Facilitates Susceptibility to Infection: Alcohol has been shown to facilitate in vitro HIV infection of human lymphocytes and mononuclear cells, and to enhance survival of Mycobacterium avium (M. tuberculosis) in macrophages. Alcohol also inhibits the synthesis of chemotactic factors and release of oxidants by alveolar macrophages. Equally important, alcohol inhibits activity of Tumor Necrosis Factor in serum and in lung macrophages which may play a role in impaired host defense against opportunistic infections and malignancy.

Maternal Alcohol Use Depresses the Immune System Development in the Newborn: Recent findings indicate that maternal alcohol consumption during pregnancy has a profound effect on the development of the fetal immune system. Ethanol inhibits transport of antibodies across the placenta, suppresses proliferation and maturation of thymocytes, and decreases the offspring's ability to resist infections. The latter effect also has been shown for paternal alcohol consumption. Recently, a new study has been initiated to investigate effects of prenatal alcohol consumption on regulatory interactions between the endocrine and immune systems. Further research in this area is needed to clarify the possible role of alcohol as a cofactor of maternal transmission of HIV to the fetus and its increased susceptibility to other infections.

Alcohol Inhibits Cellular and Humoral Immunity: Studies continue to explore the spectrum of inhibiting effects of alcohol on both cellular and humoral components of immune response (on natural killer cells, on function of helper and suppressor T-lymphocytes, and on antibody-secreting B-lymphocytes). Research in this area is crucial in understanding mechanisms of alcohol's effects on host resistance to HIV and opportunistic infections.

Alcohol Use is High Among Groups With "High Risk" Sexual Behavior: Prospective and cross-sectional studies on the associations between alcohol/drug use and high risk sexual behavior indicate that various high risk populations, including homosexual and bisexual men and minority groups in different geographic areas, tend to use/abuse alcohol more often than others. In an epidemiological study, homosexual and bisexual men with high risk sexual behavior (unprotected sex), were found to use alcohol more often than "low risk" men. The mean percentage of sexual occasions on which alcohol was used before or during sex was also higher for "high risk" men. Men who were engaged in both unprotected and protected sex were significantly more likely to report alcohol or drug use and the feeling of being intoxicated or high during unprotected anal sex.

Effective Approaches for Prevention of Alcohol-Related Risky Sexual Behavior: While epidemiological studies reveal an association between alcohol consumption and the risk of HIV infection, NIAAA-supported prevention research projects study the role of alcohol in facilitating high-risk behaviors. Furthermore, these studies highlight the underlying psychosocial and behavioral mechanisms in different populations, including adolescents, women and minorities, in order to develop and evaluate culturally relevant strategies contributing to prevention of unsafe sexual practices. NIAAA has funded a number of studies in the area of prevention research. Although most of this research is in an early stage, preliminary data obtained in a heterosexual population of adolescents indicate that teenagers who consumed five or more drinks daily were almost three times less likely always to use condoms. Among teenagers who ever had

sex after drinking, a significantly smaller number used condoms than others who had sex without using alcohol. Alcohol use particularly predicts sexual risk taking on the first occasion of intercourse with a new sexual partner. Further research in this area will facilitate understanding of the relationship between alcohol abuse and intoxication on the one hand and high risk behavior on the other as well as development of effective approaches to prevention.

Training and Curricula Development: In addition to the extramural research projects, NIAAA initiated training in AIDS-related alcohol research and has supported collaborative projects to develop and test AIDS and substance abuse curricula for primary care physicians and alcohol and drug abuse treatment personnel.

Intramural Research

Research on alcohol's role as a co-factor in the etiology of AIDS, and as a promoter of opportunistic infection in patients suffering from AIDS, is a major component of the Intramural Research Program. An additional area of AIDS-related research initiated within the Intramural Program is the examination of the effects of the AIDS virus on neuronal function. Current research is focusing on determining the effects of AIDS on the immune system, such as investigating the factors controlling T-cell maturation and proliferation, the events that follow binding of the AIDS virus to receptors on lymphocytes, the effects of gp120 and related viral coat proteins on neuronal function, and the mechanisms by which the AIDS viral coat proteins change neuronal metabolism and produce AIDS-related dementia.

Alcohol and Lymphocytes: Investigations of alcohol's effect on the immune system have enabled the Intramural Program to begin to explore systematically research findings it has developed on the effect of alcohol on lymphocytes. Intramural research scientists, working in collaboration with Walter Reed scientists, have demonstrated that animals that are chronically treated with alcohol have significantly reduced numbers of lymphocytes in the peripheral blood, spleen, and thymus. Furthermore, the remaining cells in the immune system have diminished ability to divide and proliferate. Significant efforts are now being made to understand how lymphokines control lymphocyte proliferation. To this end, an enzyme involved in controlling lymphokine-regulated T-cell maturation and proliferation has been isolated and purified. These studies will set the stage for detailed analysis of alcohol's mechanism of action and may also contribute to the development of novel factors for stimulation of T-cell production in AIDS patients. The effects of exposure to AIDS virus coat proteins on human lymphocytes are also being examined by Intramural scientists. An analysis of lymphocyte phosphoprotein metabolism under unstimulated and immuno-modulated conditions is underway. Selective alterations in phosphoprotein profile, linked to early events in T-cell activation or after exposure to

AIDS virus coat proteins, may be related to causes or symptomatic effects of AIDS.

Alcohol, AIDS, and Brain Receptor Sites: In addition, Intramural scientists are continuing their efforts in characterizing brain receptor sites that bind the AIDS virus protein components and examining alcohol's effect on these brain receptor sites. Completed studies have demonstrated that injection of AIDS protein and related materials into the brains of animals produces region-specific decreases in brain metabolism. The significant decrease in metabolism occurs with extremely small doses of the viral protein and current work is directed at identifying and determining the function of the brain receptors that bind the viral proteins. Work on these receptors suggests that the AIDS virus attacks macrophage-like cells in the brain, and this work is producing insights into how the HIV infection generates dementia in a large portion of AIDS victims.

HEALTH RESOURCES AND SERVICES ADMINISTRATION
Bureau of Health Care Delivery and Assistance

Community Health Care Services for AIDS

The community health care services for AIDS program concentrates on providing health care for persons with the AIDS/HIV infection in community health centers and migrant health centers (C/MHCs) that may ultimately help to relieve the burden on inpatient and long term care public facilities while improving efforts to mainstream the care for this population into the general health care system. These measures are consistent with HRSA's current efforts to mainstream services for the HIV infected into existing primary care networks.

In FY 1991, under Title III of the newly enacted Ryan White Comprehensive AIDS Resources Emergency Act of 1990, funding for this program has been significantly increased from \$13.3 million to \$44.9 million. The FY 1991 appropriation will continue support for grantees funded prior to FY 1991 and will support additional projects in FY 1991. In addition to C/MHCs, grants will be made to Health care for the Homeless program, family planning program grantees, comprehensive hemophilia diagnostic and treatment centers, federally qualified health centers under section 1905 (1)(2)(B) of the Social Security Act, and other nonprofit entities that provide comprehensive primary care services to populations at risk of HIV disease.

Currently, available services in many communities for persons with AIDS/HIV infection are relatively uncoordinated, fragmented, and often very expensive. Reimbursement for these services is variable and may be inadequate, particularly for out-of-hospital care, since a large and growing number of persons with AIDS are also poor and medically uninsured, or are persons covered only by Medicaid or other forms of public assistance. If a wider range of community oriented, coordinated, ambulatory health care were available, hospital costs and possibly other related costs could be decreased. Focusing resources on outpatient services, home health care, or hospice care is likely to improve continuity and reduce the cost of HIV/AIDS patient care.

In FY 1991 activities will focus on enhancing the capacity of community based organizations to offer the range of services necessary to impact on the prevention and treatment of the HIV infection. During 1991 it estimated that 100,000 people will be served through this program.

Health Resources and Services Administration
Bureau of Health Professions

Acquired Immune Deficiency Syndrome (AIDS) Activities

In FY 1990, emphasis on AIDS-related health education and professional training activities was reported among 13 of the Bureau's grant programs, involving 138 grantees. A total of \$15,188,780 was awarded to cover education and training activities.

Under the Area Health Education Center program, significant emphasis is placed on health professions training, continuing education, and patient education related to HIV/AIDS. A total of \$408,092 was awarded among 10 of the 17 AHEC projects specifically reporting AIDS activities, affecting an estimated 108,578 individuals, including students and population in the areas served by the projects.

Two of the grantees under the new Health Education and Training Centers program will provide educational programming on HIV/AIDS for an estimated 70 health professions students. The University of Washington received \$13,922 specifically for the development of their training component in this area.

Under the section 784 General Internal Medicine/General Pediatrics Residency training program, 57 grantees indicated that approximately 683 residents will benefit from training in the health care needs of the HIV/AIDS infected population. A total of \$64,162 was awarded among five of the grants for their training initiatives. Twelve faculty development grantees will train 60 faculty in developing and teaching AIDS curriculum: no specific funds were requested for this effort.

An estimated 1,864 trainees under the Physician Assistant Training Program will be exposed to health education in this area by 35 grantees. Eighteen of these programs received a total of \$256,199 for their training initiatives. A funding priority to the section 783 program was included in the FY 1990 grant cycle for those projects that demonstrate expansion of current or development and implementation of new curriculum content necessary in caring for HIV infected persons.

The purpose of the AIDS Education and Training Centers program (AIDS ETCs) funded under Section 788A is to establish a national network of training centers to provide the multidisciplinary and specialized training programs needed by the health care personnel who care for people with HIV/AIDS. During FY 1990, a total of \$13,706,698 was awarded among 15 grantees, and an estimated 300,019 health professionals benefitted from this training.

The section 786(a) Family Medicine training programs also reported educational interventions in AIDS. One predoctoral training program grantee indicated that 93 students will benefit from the HIV/AIDS training offered. Thirty graduate training grantees offer didactic and clinical training experiences in treating HIV/AIDS infected persons. Approximately 342 residents will benefit from this training and a total of \$508,640 was requested specifically for this purpose. Twenty-one Family Medicine Faculty Development grantees reported training in this area for 1,405 faculty.

Podiatric Medicine Primary Care Residency Training Program grantees will emphasize HIV/AIDS education in the training of an estimated 24 podiatry residents. A total of \$16,461 was awarded among the five grantees for this purpose.

Two Preventive Medicine Residency grantees indicated that they will offer training to seven residents in the prevention and treatment of HIV/AIDS in patients.

One Nursing Special Projects clinical center reported training activities in the treatment of HIV/AIDS infected persons. A total of \$105,292 was requested for this purpose.

Under the Advanced Nurse Education program, one grantee requested \$109,314 for their graduate school of nursing to provide training for clinical specialists who will be able to plan and provide care for AIDS patients in all settings.

Health Resources and Services Administration
Bureau of Health Resources and Development

HUMAN IMMUNODEFICIENCY VIRUS (HIV)
ACQUIRED IMMUNE DEFICIENCY SYNDROME

The HIV/AIDS functions within the Bureau of Health Resources Development included activities related to the development or support of services or resources for the HIV-infected and activities under Title XXVI of the PHS Act (enacted by P.L. 101-381, the Ryan White Comprehensive AIDS Resources Emergency Act of 1990).

Title XXVI, Part A (Ryan White CARE Act, Title I) authorizes grants to metropolitan areas with very high numbers and/or rates of AIDS cases for outpatient and ambulatory health and social support services. Fifty percent of the amount appropriated is allocated by formula and the remainder is awarded to those areas whose applications demonstrate a severe need for supplemental funds, the ability to use these funds expeditiously and a commitment of local resources to combat HIV disease. FY 1991 is the first year grants have been made under this new authority.

Title XXVI, Part B (Ryan White CARE Act, Title II) authorizes grants to States and territories for the operation of HIV service delivery consortia in the localities most affected by the epidemic, and for the provision of home and community based care, continuation of insurance coverage for infected people, and HIV treatments that prolong life and prevent serious deterioration of health. Formula grants are awarded to the States based on the number of AIDS cases, population and per capita income. States with at least 1% of total AIDS cases must use at least 50% of these funds for HIV care consortia in areas with large numbers of HIV infected persons. At least 15% of each State's allocation must be used for services to infants, children, women and families with HIV disease. States with more than 1% of the total AIDS cases with the exception of Puerto Rico are required to match Federal dollars at a rate of \$1 for each Federal \$5 in FY 1991 and at a rate of \$1 for each Federal \$4 in FY 1992. Up to 10% of the amount appropriated for this activity may be retained by the Secretary for Special Projects of National Significance.

Since 1986, with the assistance of HIV Service Demonstration grants in high HIV incidence metropolitan areas, progress has been made towards the development of comprehensive service delivery systems. The grants have supported coordination and regionalization of health care resources, and have begun the necessary integration and collaboration of resources and responses. By the end of FY 1990, \$68.2 million had been awarded to a total of 25 locations.

By the end of FY 1990, \$78,064,000 including \$5 million from private industry had been distributed to states and insular areas to provide financial help to pay for drugs determined to prolong the life or prevent serious deterioration of health of people with AIDS or HIV infection. States have used these funds to reimburse for drugs for low-income individuals whose drugs are not covered by Medicare, state Medicaid or other third party payers. The states must define low-income for the purposes of this program.

In FY 1990 HRSA awarded grants totaling \$18.6 million to states to encourage the development and provision of home and community-based health services. The availability of home health services under a plan established by a health care professional, can be a desirable alternative to a sub-acute care facility or the more expensive alternative of hospitalization.

In FY 1990 \$1.4 million was awarded to establish three demonstration projects in geographically diverse areas. Their purpose is to provide limited support for the development and operation of subacute care facilities to assist in maintaining AIDS patients.

The Bureau also manages a grant program designed to assist in renovation or construction of non-acute care facilities for persons with HIV infection. Their care needs are often too broad and too intensive to be appropriately provided by existing non-acute care facilities. Anecdotal evidence indicates that HIV infected patients unnecessarily remain in hospitals because there is an inadequate number of sub-acute care facilities to receive patients upon discharge from the hospital. Since FY 1988 \$14.7 million has been made available for this activity.

OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH

Office of Minority Health

Acquired Immune Deficiency Syndrome

The Office of Minority Health was established to be the focal point for the implementation of the recommendations contained in the Secretary's Task Force Report on Black and Minority Health and for the formulation and development of policies affecting minority health. The Office works closely with the Public Health Service agencies and other components of the Department to assure that minority health care needs are a priority in Departmental resource allocation decisions.

Since the issuance of the Task Force Report in 1985 and the establishment of the Office of Minority Health, AIDS has also been identified as an excess killer of minorities. The Office, therefore, has a mission regarding AIDS which is similar to the work being done in the six causes of excess deaths identified in the Task Force Report.

Over 40 percent of all AIDS victims are Black or Hispanic. These populations have different risk factors and demographic profiles from the majority population. These differences, compounded oftentimes with cultural/language differences, require alternative strategies to convey disease prevention information. The Office of Minority Health's AIDS activities focus on the following education and prevention efforts:

- Supporting the development of culturally sensitive and culturally appropriate educational materials.
- Conducting technical assistance programs to help minority organizations design, implement and evaluate effective prevention/intervention programs. These efforts include identifying regional technical assistance resources and sponsoring regional technical assistance workshops.
- Assisting minority community-based organizations in the dissemination of AIDS information through the Minority Community Health Coalition Grant Program as well as through the AIDS Education/Prevention Grant Program.

The Minority Community Health Coalition Grant Program provides funding to support innovative community-based disease risk reduction demonstration projects. These grant projects are based on the concept that greater force for change can be achieved by expanding the base of community awareness, support and involvement. This is particularly true if such efforts are carried out by influential community institutions such as churches, schools and clubs which are organized by recognized

community leaders. One or two of these grants awarded each year are targeted to AIDS education and prevention.

The AIDS Education/Prevention Grant Program is a separate grant program created to demonstrate the effectiveness of AIDS/HIV infection education and prevention strategies targeting racial and ethnic minority populations. These grants are awarded to national minority organizations and community-based organizations. These grants expand the range of community-based and national organizations involved in AIDS education/prevention activities and encourage innovative approaches that appropriately address the diversity within and among minority populations.

The Office is also responsible for coordinating PHS efforts to provide national and regional forums which explore the multiple issues related to HIV/AIDS in racial and ethnic minority populations. As an example, the OMH conducted a national conference on AIDS and HIV infection in racial and ethnic minority populations in 1989 and will be conducting seven regional conferences that will focus on issues specific to each region. The seven regional conferences will serve as the springboard for a national meeting tentatively scheduled for the summer of 1992.

INDIAN HEALTH SERVICEAcquired Immune Deficiency Syndrome (AIDS)

The Indian Health Service (IHS) mission for addressing AIDS and the HIV epidemic is to prevent further spread of the infection to American Indian and Alaska Native communities and to treat those already infected.

To fulfill this mission, the IHS has implemented a program of surveillance, risk assessment and prevention for health care workers and Indian communities, and treatment of HIV infected persons.

As of September 1990, there were 218 cases of AIDS in American Indians and Alaska Natives (CDC HIV/AIDS Surveillance, September, 1990). The IHS has identified and is following 33 cases of AIDS and an additional 172 HIV seropositive Native Americans that may require treatment in fiscal year (FY) 1992. AIDS is seen predominantly in urban areas but the ongoing blinded seroprevalence survey of prenatal, Sexually Transmitted Diseases (STD), and Tuberculosis (TB) clinics has demonstrated the presence of the virus in remote Indian communities.

The IHS has requested \$3,210,000 and 14 FTEs for the 1992 AIDS Program. This represents an increase of \$1,407,000 over the FY 1991 appropriated budget of \$1,803,000. The IHS plans to spend the funds on epidemiologic studies and surveillance (\$850,000), individual and community prevention activities (\$2,060,000), patient care services including ambulatory drug therapy (\$300,000). The 34 IHS urban Indian programs will be allocated \$646,000. The Health Education Program will receive \$497,000 for prevention activities. The increased funds will be obtained from private insurance and other third party collections.

The FY 1992 request will allow IHS to continue and improve its AIDS/HIV prevention/intervention activities. Permanent HIV/STD Coordinators will be established in each Area to monitor all HIV infections in its service population and coordinate surveillance activities with local, State and Federal entities.

The IHS will continue training a multi-disciplinary cadre of health personnel to provide HIV education and counseling for pre- and post-HIV testing. Psychosocial support for HIV-seropositive individuals and their families will also be provided.

The IHS, in collaboration with the Bureau of Indian Affairs (BIA), will continue AIDS Prevention/Risk Reduction Services to all reservation based schools, school boards, and educators, as well as, Teen Clinics, Youth Substance Abuse Treatment Centers and other youth organizations.

The IHS will sustain training and information activities to provide health education and risk reduction messages to the general American Indian and Alaska Native population and specific groups including women, youth, and individuals practicing high risk behavior.

The IHS will train and update health care workers on appropriate actions to protect themselves and the patients.

The IHS will continue to follow and treat HIV infected American Indians and Alaska Natives.

Background Information:

FY 1988

In FY 1988, the IHS placed special emphasis on the development of a national AIDS prevention program. This program was assigned to the Clinical Support Center in Phoenix, Arizona, and the interagency AIDS liaison function was assigned to the Headquarters Special Initiatives Branch. The IHS sought assistance for its AIDS program from private and government agencies in order to provide a more comprehensive program.

- o The IHS signed a memorandum of agreement with the Centers for Disease Control (CDC) in FY 1988 to provide funds for the implementation of a prevention program consistent with CDC standards. The IHS received \$500,000 from this and used \$350,000 in FY 1988 and \$150,000 in FY 1989. To date, over 3,000 IHS personnel have received HIV Counselor training, and all IHS Health Care Workers have received AIDS prevention education.
- o A memorandum of agreement with the BIA in FY 1988 jointly funded several seminars designed to prepare joint IHS-BIA teams to teach AIDS prevention to an estimated 40,000 school children. The IHS has provided AIDS Prevention/Risk Reduction Services to all reservation based schools, school boards, and educators, as well as Teen Clinics, Youth Substance Abuse Treatment Centers and other youth organizations. Regular training sessions have been provided to BIA school administrators, teachers, and school board members.
- o A memorandum of agreement in FY 1988 with the Administration on Native Americans (ANA) and the Red Cross provided funds and educational materials to support AIDS activities in Urban Indian Projects. The IHS received \$60,000 from the ANA.

FY 1989

Eight hundred thousand (\$800,000) dollars was appropriated for the IHS AIDS Program and was used to continue the AIDS prevention activities. Three hundred thousand was specifically allocated to IHS Urban Indian Programs for AIDS prevention education; \$258,000 was used for reservation based prevention programs; and \$242,000 was expended for AIDS drugs and AIDS treatment.

Eleven-hundred sixty-eight (1168) individuals in IHS and Tribal programs were trained as HIV counselors resulting in requests for 1800 confidential HIV tests from persons with high risk behavior.

The IHS in cooperation with American Indian and Alaska Native AIDS organizations, CDC and various states have developed 14 Native American AIDS videos, 20 culturally specific pamphlets and over 30 posters dealing with HIV.

In May 1989, a continuing educational conference was held in Phoenix, Arizona for 150 IHS mid-level practitioners. This educational program was video-taped and made available to all IHS Health Care Workers (HCW) for Category I Continuing Medical Educational (CME) credit. Over 650 IHS HCWs used this program in the first three months it was made available. The IHS also revised and distributed 200 of copies the IHS Clinician's Guide to AIDS, a collection of current preventive and clinical AIDS information for IHS providers.

The CDC Interagency Agreements provided IHS with additional funding: \$150,000 from the Center for Prevention Services for HIV prevention and \$254,865 from the Center for Infectious Diseases for Seroprevalence studies.

FY 1990

The IHS received \$978,000 from the combined PHS HIV/AIDS budget. Fifty thousand dollars was used for surveillance activities, \$622,000 was used for education and prevention activities, and \$308,000 was used for treatment activities. An additional \$325,000 of the education/prevention funds were specifically allocated to the Urban Indian Program. Much was accomplished during FY 1990:

- o Each Area Office networks with their respective state epidemiologists in the reporting of STDs in American Indians and Alaska Natives. All programs must meet state reporting requirements. Information is shared with the states and CDC.
- o IHS designated a permanent FTE for the AIDS Coordinator located at the Technical Support Center in Albuquerque.
- o An additional 1,800 individuals were trained as HIV counsellors encouraged 2,708 request for HIV tests.

- o Women seen in prenatal and other clinics directed toward women are being screened for risk-taking behavior. A similar screening is being done in STD and TB.
- o The IHS has provided AIDS Prevention/Risk Reduction Services to all Indian communities. About 95% of the IHS service population has heard or seen an AIDS education message.
- o The IHS pilot tested a film series on Universal Precautions at six IHS sites involving 1,200 IHS Health Care Workers (HCW). This program proved to be an effective medical education tool in a busy clinical setting and will be made available to additional sites.

The CDC interagency agreements provided additional funding: \$500,000 to continue prevention and education services; \$433,675 for continuation of seroprevalence studies; and \$70,000 for STD surveillance.

FY 1991

The IHS will continue its surveillance, prevention education, intervention, and treatment activities during FY 1991. Additional funding budgeted to the Urban Indian Programs (\$346,000) will be used to expand the outreach, intervention and treatment activities in urban Indian areas. Additional funding budgeted to Health Education (\$497,000) will be used to target prevention activities for women, children and tribal leaders.

The CDC interagency agreements will provide additional funding as follows: \$518,000 for continuation of seroprevalence studies, \$500,00 for specific prevention efforts, and \$325,000 for STD surveillance.

Table 1
IHS AIDS/HIV FUNDING LEVELS

Fiscal Year	Amount	Source	Total
1988			
Prevention	\$ 350,000	CDC (CPS)	
Prevention	60,000	ANA	
Prevention	70,000	BIA	
Total	\$ 480,000		\$ 480,000
1989			
Prevention/Rx	800,000	IHS	
Prevention	150,000	CDC (CPS)	
Seroprevalence	254,865	CDC (CID)	
Total	\$ 1,204,865		\$ 1,204,865
1990			
Prevention/Rx	\$ 978,000	IHS (IAA) ¹	
Prevention	500,000	CDC (CPS)	
Seroprevalence	433,675	CDC (CID)	
STD	\$ 70,000	CDC (CPS) ²	
Prevention/Rx	\$ 2,670,660	IHS ³	
Total	\$ 4,652,335		\$ 4,652,335
1991			
Prevention/Rx	\$ 1,803,000	IHS	
Prevention	\$ 500,000	CDC (CPS) ⁴	
Seroprevalence	518,233	CDC (CID)	
STD	325,000	CDC (CPS)	
Total	\$ 3,146,233		\$ 3,146,233
1992			
Prevention/Rx	\$ 3,210,000	IHS ⁵	
STD	325,000	CDC (CPS)	
Total	\$ 3,535,000		\$ 3,535,000

¹ Financed by PHS funds through interagency agreements with CDC, AHCPR and NIDA

² Aberdeen, Albuquerque, Alaska, Oklahoma, Phoenix, and Portland Areas

³ Financed from IHS Base Budget not Identified as AIDS funding

⁴ Albuquerque, Aberdeen, Oklahoma, Phoenix, Portland Areas

⁵ Includes \$1,407,000 to be financed with insurance collections

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

ACQUIRED IMMUNODEFICIENCY SYNDROME

The purpose of the Agency for Health Care Policy and Research (AHCPR) is to enhance the quality, appropriateness, and effectiveness of health care services and to improve access to that care. This is accomplished through the establishment of a broad base of scientific research and through the promotion of improvements in clinical practice and in the organization, financing, and delivery of health care services. The AHCPR also is responsible for facilitating the development, review, and updating of clinically relevant guidelines for specific conditions and treatments. As the focal point of Federal efforts in medical effectiveness and health services research, the AHCPR seeks to create and disseminate new knowledge and better understanding of the processes by which health services are made available and how they may be provided more efficiently and effectively. It addresses the full array of health care issues, among them AIDS and other illnesses related to the human immunodeficiency virus (HIV).

The set of health services associated with HIV illness is enormous, complex, and changing. It includes preventive services for people at risk of infection, testing and counseling services, outpatient medical and mental health services for those with early symptoms, and a combination of inpatient and outpatient services for persons with AIDS. It involves bringing to bear medical knowledge that is constantly changing, coordinating services provided by a myriad of providers, and bringing into the health care system people who have historically remained outside.

The complexity, urgency, and unique aspects of the HIV epidemic demand a strong program of health services and medical effectiveness research. Activities addressing HIV illness are carried out through several programs: general health services extramural research; general health services intramural research; research dissemination and liaison (including State and local user liaison) and medical treatment effectiveness.

General Health Services Extramural Research

The Agency's Center for General Health Services Extramural Research has a multi-faceted approach to HIV health services research. The centerpiece of this program is the support of research, through peer-reviewed grants and contracts. In addition, the extramural research program provides extensive technical assistance and policy analysis, facilitates timely dissemination of research findings, and works collaboratively with all concerned to assure that activities are coordinated.

Projects Completed in Fiscal Year 1990:**"AIDS and Insurance: The Experience of a High Risk Cohort"**

Nancy Kass, Johns Hopkins University, Grant Number: HS 06108

This dissertation grant examined the insurance experiences of a sample of gay and bisexual men. Self-administered questionnaires were distributed (1) to participants in the Baltimore and Los Angeles sites of the Multicenter AIDS Cohort Study, (2) to gay male AIDS patients at the Johns Hopkins Hospital and (3) to male leukemia patients at the Johns Hopkins Hospital. Results from this non-representative sample suggest that although persons with AIDS are not significantly more likely to be uninsured than persons who do not have AIDS, they are thirty-six times as likely to have Medicaid coverage. Six percent of the sample has been screened for HIV by the health insurance company, 8% by a life insurance company, and 7% by a disability company. Persons with AIDS were five times as likely to report HIV-related discrimination from employers as persons who do not have AIDS. Eighteen percent of persons with AIDS reported having been refused treatment by a doctor or dentist due to a known or suspected HIV-related condition, compared with 5% of seropositives and 1% of seronegatives.

Projects Ongoing in Fiscal Year 1990:**"AIDS Cost and Service Utilization Survey" (ACSUS), Westat, Inc., Rockville, MD, Contract No. 282-89-0020**

ACSUS is a national survey to collect uniform data on the utilization and costs of health and social services for persons with AIDS and other HIV-related illnesses. Interviews will be conducted every 3 months over an 18-month period, with a sample of approximately 1900 adults and adolescents plus 100 children. In addition to medical care, respondents will be asked about their use of social, mental health, and oral health services, informal social supports, barriers to care, employment history, and quality of life. Interview data will be supplemented by information abstracted from patient records and information supplied by providers and insurers.

These sources will provide a comprehensive picture of the direct and indirect costs of medical and support services, during various stages of HIV-related illness. Data will include third-party and out-of-pocket payments, for both inpatient and outpatient care, including care received in physicians' offices, ambulatory clinics, and the patient's home. Utilization and charges for the services of physicians, nurses, and other health care workers will be obtained, as will charges for drugs, medical supplies, and devices.

Final products of the contract will include documented data tapes for use by the research community. In addition, ACSUS data will enhance AHCPR's capacity to provide timely input to policy

questions. The data will support examination of utilization, cost, and access across HIV exposure categories (e.g., homosexual, heterosexual, or intravenous drug use), stage of illness, demographic characteristics, geographic area, and payment source. By addressing the full spectrum of HIV-related illness and the range of health care providers and payers, ACSUS will provide a rich source of data for research and the basis for policy-relevant analyses concerning the utilization and costs of health care services associated with HIV illness.

Allison-Cooke, Sherry, Ph.D., National Perinatal Information Center, "Pediatric AIDS: Local Responses, Service Use, and Cost," Grant No. HS 06271

This project will provide both longitudinal and cross-sectional data about the utilization and costs of inpatient and outpatient care for infants, children, and women with AIDS. One aspect focuses on discharge, billing, and cost data from 10 hospitals in 5 urban areas with high incidence of pediatric AIDS and will analyze trends from 1987 to 1991. In addition, detailed case studies will be developed to address questions about alternate community responses to meeting the health care needs of women and children with AIDS and to obtain information on outpatient services.

Andrulis, Dennis P.; National Public Health and Hospitals Institute, "1987 U.S. Hospital AIDS Survey," Grant No. HS 06129

A survey conducted in over 600 hospitals will assess the financial and programmatic impact of AIDS on U.S. hospitals and will permit comparisons with 1985 data. Variables include demographic characteristics of the patient populations, financing of care, and types of services provided. The 1987 data include a survey of pediatric cases and a study of costs related to the use of AZT. Analysis will focus on differences due to geographic location and hospital type, as well as changes over time.

A report from this research was recently published, Hintz, E. A., Weslowski, V. B., Andrulis, D. P. "AIDS Care in Public Hospitals; Responses from NAPH Member Hospitals to the U.S. Hospital AIDS Survey 1985-1988", The National Public Health and Hospital Institute, November 1990. This document discusses findings from the U.S. Hospital AIDS Survey for the membership of the National Association of Public Hospitals (NAPH). The researchers are currently analyzing hospital data from 1988 which will be compared with trends from previous years. The 1988 analysis incorporates responses from over 700 institutions treating more than 22,000 people with AIDS during that year.

Avorn, Jerome; Beth Israel Hospital, "Improving the Accuracy of Transfusion Decisionmaking," Grant No. HS 05300

This is a multicenter, randomized, controlled trial of an educational intervention designed to improve the cost

effectiveness and clinical appropriateness of blood product utilization. It measures the effect of the intervention on the use of blood products and identifies patient and physician characteristics that enhance or impede this effect. Clinical appropriateness is defined in terms of reduced risk of transmitting diseases, including hepatitis and AIDS. AVORN

In preparation for a larger scale intervention program, Dr. Avorn and his colleagues conducted a survey to assess physicians' knowledge of the risks of and indications for red blood cell transfusions, their perceptions of the importance of nonclinical factors, including resource availability, peer influence, cost, and hospital guidelines, and the "practice style" dimensions of confidence and interventionism. Widespread deficiencies were found in physicians' knowledge of transfusion risks and indications. Each transfusion risk was estimated correctly by fewer than half of those surveyed, and only 31% responded correctly to a set of four questions regarding transfusion indications. Attending physicians routinely had lower knowledge scores than did residents, yet they exhibited more confidence in their knowledge. Residents' transfusion decisions, however, were strongly influenced by the desires of their attending physicians, resulting in their ordering potentially inappropriate transfusions. Of the residents surveyed, 61% indicated that they ordered transfusions that they judged unnecessary at least once a month because a more senior physician suggested that they do so. These findings provide the insights for the intervention strategies now being tested which address the dual concerns of quality of care and cost containment. These findings were published in Journal of the American Medical Association, Vol. 264, No. 4, July 25, 1990.

Blendon, Robert Jay; Harvard U. School of Public Health, "Discriminatory Attitudes and Knowledge about AIDS," Grant No. HS 06379

This is a secondary analysis of public opinion survey data to examine the relationship between hostile attitudes toward persons who are infected with HIV and misinformation about how the virus is transmitted. Data come from surveys conducted by the Roper Center for Public Opinion Research, the Gallup Organization, and the Los Angeles Times, among randomly selected, national household samples, since 1985. Variables include knowledge and beliefs about how HIV is transmitted, demographic characteristics, attitudes, and moral judgments about persons who are infected. Findings will inform the policy debate regarding the need for antidiscrimination legislation to protect individuals infected with HIV.

Colombotos, John; Columbia University, "Physicians, Nurses, and AIDS: A National Study," Grant No. HS 06359

The researchers will conduct a national survey of physicians and nurses to obtain data on how their knowledge, attitudes, risk

perceptions, practices, and career plans relate to AIDS. Descriptive findings will be extended through analyses of the interrelationships among these variables, e.g., the relationship between knowledge about AIDS and willingness to treat AIDS patients. Variations associated with respondents' professional characteristics and personal background will be studied. Other analyses will focus on the influence of geographic location, comparing health care workers from San Francisco with those from New York/New Jersey, and examining the possible influence on health care workers of the cumulative AIDS caseload in their State.

Crystal, Stephen; Rutgers University "Health Care Costs and Utilization in AIDS Home Care," Grant No. HS 06339

This is an in-depth study of the utilization and costs of health and social services for participants in New Jersey's Home and Community-based Services Waiver for Persons with AIDS/ARC -- i.e., the AIDS Community Care Alternatives Program (ACCAP). Data sources include complete Medicaid payment records for all program enrollees, case management records, and personal interviews conducted monthly with 400 new enrollees, for up to 18 months. A combination of cross-sectional and longitudinal analyses will focus on service utilization across subgroups of persons with AIDS-related illnesses, including ethnic minorities, women, and children; the interrelationships among home care, institutional care, and social supports; and differences in utilization and costs for persons who are, and those who are not, enrolled in ACCAP.

Epstein, Arnold M., Harvard U. School of Public Health, "Costs, Correlates and Outcomes for Persons with AIDS," Grant No. HS 06239

Investigators will collect and analyze information on the use and costs of medical services and outcomes for a cohort of approximately 500 AIDS patients who receive primary care at one of three Boston-area providers. Data will include the costs of a wide range of inpatient and outpatient services, as well as indirect costs associated with disability and premature mortality. Data on patient clinical characteristics, stage of illness, functional status, and socioeconomic status will be used to explain costs and to predict costs, utilization, functioning, satisfaction, and survival.

Fleishman, John A.; Brown University, "Delivery of Home Care for People with AIDS," Grant No. HS 06378

This grant will obtain information about the availability and organization of home health services for people with AIDS. Data will be collected from a sample of eight home health care agencies, providing different levels of service to persons with AIDS, in nine cities with varying incidence of AIDS. Issues to be addressed are: 1) organizational characteristics of agencies

that provide various amounts of care to AIDS patients; 2) organization of AIDS services within these agencies; 3) coordination with other service providers; and 4) problems in delivering home care to AIDS patients. Analysis will include both descriptive statistics and formulation of multivariate models to help explain home care agencies' involvement with the AIDS population.

Fries, James J.; Stanford University Medical School, "ATHOS -- AIDS Time-Oriented Health Outcome Study," Grant No. HS 06211

This study will develop a prospective, longitudinal information system on 5,000 to 8,000 AIDS, ARC, HIV-positive, and at-risk subjects in California. Clinical, laboratory, economic, and quality of life data will be obtained from 5 private practices and 5 indigent clinics. Analyses will include: factors influencing transition between clinical states, quality of life, patient outcome, and costs; as well as assessment of both direct and indirect costs and efficacy of both approved and unapproved therapies.

Hay, Joel W.; The Hoover Institution, Stanford University, "Projecting the Costs of AIDS/ARC in the United States," Grant No. HS 06092

The objective of this research is to develop a model for projecting costs related to AIDS and ARC that can be easily modified as new epidemiological information and treatments become available. Using the Medi-Cal AIDS patient database and data for two other regions, the researchers will refine and validate results of an earlier study. The model will permit estimation of lifetime costs per patient based on medical diagnosis and treatment decision tree algorithms.

Hogan, Andrew J.; Michigan State University, "Costs of Health Services for HIV Infected Individuals," Grant No. HS 06260

Using Medicaid records and some private health insurance data, this project will study use and cost of services for HIV-related illnesses between January 1984 and March 1989 in Michigan. Hypotheses focus on differences in use and cost by risk group and sex, on the impact of AZT on average monthly Medicaid payments, and on apparent underutilization of services by some Aids patients.

Kanouse, David E.; The Rand Corp., "The Quality of Care in AIDS: Pneumocystis Carinii Pneumonia," Grant No. HS 06016

This project will examine the impact of patient characteristics, disease, and processes of care on clinical outcomes for AIDS patients and develop predictors of clinical outcomes. Data are based on hospital records of 600 newly diagnosed AIDS patients in Southern California with an initial episode of pneumocystis carinii pneumonia.

Keenan, Joseph M.; University of Minnesota, "Research Agenda on the Community-Based Care of Persons with AIDS," Grant No. HS 06224

This grant supported a conference on research problems and issues related to home and community-based care for AIDS patients. The purpose of the conference was to identify and prioritize research issues related to appropriate care settings, quality of care, cost, health care policy, and both lay and professional caregivers. The conference met in Minneapolis, August 14-16, 1989.

Kelly, Joyce V.; Association of American Medical Colleges, "AIDS and Medical Residency Selection in New York, San Francisco, and Los Angeles," Grant No. HS 06428

This project will examine the effects of the AIDS epidemic on the selection of post-graduate training by senior medical students in three cities with very high AIDS caseloads. Available data on medical students, residency programs, and residency matches will be linked with measures of the prevalence of AIDS in residency hospitals, to create a new database for this and future studies. Specialty choice and preferred hospital location will be analyzed in terms of student background, exposure to AIDS in medical school, student test scores, and characteristics of the residency programs. Trends between 1983 and 1988 will be examined.

Lambright, W. Henry; Syracuse Research Corp., "The New York State Response to AIDS," Grant No. HS 06184

New York State's emergency response to AIDS, especially the work of the AIDS Institute, will be studied. The focus will be on the coordinating role of the Institute and its regional outreach organizations. By identifying factors that have led to success and to problems in coping with AIDS in New York, the investigators will define a model administrative organization that other States may replicate.

Mor, Vincent; Brown University, "Longitudinal Study of AIDS Health Services Use and Costs," Grant No. HS 06214

This project will build upon an evaluation of the Robert Wood Johnson Foundation's AIDS Health Services Demonstration by reinterviewing 1,224 patients from 9 to 12 months after their initial evaluation interview. Hospital, clinic, physician, and home care service use records will also be abstracted. The overall goal is to describe patterns of medical and social service use by persons with AIDS, to determine the degree to which their needs are met, and the degree to which their preferences for palliative versus aggressive treatment alter as their disease progresses.

Pagano, Marcello; Harvard U. School of Public Health "Modeling

Methodology for Projecting the AIDS Epidemic," Grant No. HS 06183

The researchers will develop a statistical simulation model for studying the progression and spread of AIDS, to permit predictions of the epidemic's future course and to assess the impact of potential interventions. Based on express time transitions as a stochastic progression, the model will incorporate uncertainty about model parameters.

Paringer, Lynn, Ph.D., Western Consortium for Public Health, **"Determinants of Individual Demand for HIV Testing" Grant No. HS 06352**

The purpose of the project is to identify the determinants of individually initiated demand for HIV testing (as distinct from mandated testing and third-party initiated demand) through the analysis of data from a supplemental survey on AIDS Knowledge and Attitudes (1987-1989) which was supported by the National Center for Health Statistics. The project is designed to also examine changes in demand over the study period and to stimulate demand under different assumptions. The overall goal of the study is to examine how various factors impact on an individual's decision to receive an HIV test. With the individual as the unit of observation and analysis, the study has the potential to go beyond other studies, which were descriptive or bivariate in nature, on HIV testing to more fully explore the data on demand for HIV testing.

Pascal, Anthony H.; Rand Corp., **"Financing Treatment Costs for IVDA AIDS Patients," Grant No. HS 06130**

Based on a random sample of AIDS patients affiliated with one New York City hospital, data will be collected to assess the cost burden of treatment for a panel of 50 intravenous drug abusers. Data on costs, payments, patient economic variables, and service utilization will be used to construct longitudinal profiles of these patients.

Payne, Susan McNair Cobb; Boston University **"Validating Hospital Discharge and AIDS Surveillance Data," Grant No. HS 06426**

This study will investigate the feasibility of using routinely collected hospital discharge data from Boston's Uniform Hospital Discharge Data Set to track hospital utilization and charges for patients with AIDS. Patients and their patterns of hospital utilization and charges will be described. By cross-validating these data with surveillance data, the investigators will assess the completeness of AIDS case reporting.

Seage, George R.; Boston Dept. of Health and Hospitals, **"Variation in Cost of AIDS Related to Gender and Risk Status," Grant No. HS 06150**

This study will obtain data for the State of Massachusetts on the cost and utilization of inpatient services by all women and intravenous drug users diagnosed with AIDS from January 1987 to January 1989. Estimates will be made of costs per patient, controlling for stage of disease, site of hospitalization, socioeconomic status, and levels of social support. These data will be compared with data for a sample of male homosexuals/bisexuals diagnosed during the same period.

Shortliffe, Edward H., M.D., Stanford University, "Computer Support for Protocol-Directed Therapy," Grant No. HS 06330

The purpose of this study is to develop computer-based techniques for clinical data and knowledge management of therapeutic interventions. The investigators will build T-HELPER I, a data-management environment for patients with HIV infection. T-HELPER I will provide a graphical medical record that will allow the physician user to review past data and to enter new information while perusing textual information regarding protocols according to which the patient is being treated or for which the patient might be eligible. They also will build T-HELPER II, an enhanced version of T-HELPER I that will incorporate active decision-support capabilities to encourage compliance with protocol-based therapy. T-HELPER I will be installed at a large county hospital AIDS clinic. T-HELPER II will be developed at a second, comparable county hospital AIDS clinic. Baseline data will be gathered at both performance sites and at a third control clinic where no computer system has been introduced. The computer systems will be evaluated at both sites, assessing the effect of each version on the completeness of data collection, protocol compliance, and physician satisfaction. It is expected that the development of computer-based decision support systems of this type will assist in the optimization of patient management strategies and that such systems will be adaptable over a range of diseases and conditions.

Sowell, Richard L.; Medical College of Georgia, "The Effect of Case Management on Cost of Care for PWAs," Grant No. HS 06315

This study will compare the cost of two alternative approaches to delivery of health care to persons with AIDS. The subjects are men, ages 20 through 49, who died of AIDS, in Georgia, between 1986 and 1989. A case management approach will be compared with a less organized, ad hoc approach to care, in terms of lifetime costs. Data will be drawn from medical and financial records at four hospitals throughout Georgia.

Stoeckle, John D.; Massachusetts General Hospital, "Living Wills: For Primary Care, AIDS, and Cancer Patients," Grant No. HS 06120

Patients seen in primary care physician practices, patients with AIDS, and patients on a telephone registry will be interviewed to obtain information about the "durability" of their

positions on living wills. Descriptive and analytic information will be used to tailor pre-drafted living will forms to better meet the needs of patients whose situation and treatment preferences might change. Preliminary findings suggest that discussions about treatment options in physicians' offices enable patients to make specific choices and may later improve adherence to those choices.

Williams, Sankey V.; University of Pennsylvania, "Developing Tools to Study Resource Consumption in AIDS," Grant No. HS 06230

This pilot project will develop methods that use computerized hospital data-reporting systems to identify AIDS patients and improve understanding of the costs of care and patterns of inpatient resource use for AIDS patients. Discharge data from Philadelphia's five medical school teaching hospitals will be studied for a 30-month period. Resource consumption patterns within and between hospitals will be compared. survival analysis (Cox proportional hazards modeling).

New Starts in Fiscal Year 1990:

Andrulis, Dennis P.; National Public Health and Hospitals Institute, "1988 U.S. Hospital AIDS Survey," Grant No. HS 06445

This project will assess the financial and programmatic impact of AIDS on U.S. hospitals in the third iteration of a large national survey of community, teaching, public, parochial, and pediatric hospitals. Results will be compared to those obtained in the 1985 and 1987 iterations of the survey. (See Ongoing projects.)

Bennett, Charles L., M.D., Ph.D., The RAND Corporation, "Variations in Care of AIDS Patients with 1st Episode PCP" Grant No. HS 06494

Based upon 1,600 patient records from 15 hospitals in each of four cities, the course of first episodes of Pneumocystis carinii pneumonia (PCP) will be studied, examining both outcomes (in-hospital deaths, readmissions, complications, discharge destinations, and resource use) and process. Severity of illness will be scored based upon clinical measures such as arterial blood gas oxygenation, respiratory rate, and radiographic changes; APACHE II scores; and numbers or comorbidities. Data will come from the medical records and hospital discharge abstracts. Analyses will seek relationships at the level of the patient, the physician, the hospital, and the geographic area.

Duffy, Pam R., Ph.D., University of Arizona, "Health Care Workers Overcoming Fear of HIV Contagion," Grant No. HS 06448

This project will develop a model explaining the process used by health care workers to overcome fear of occupational HIV infection in order to provide care to people with AIDS.

Specifically, the following three research questions will be addressed: (1) How do health care workers successfully manage their fear of occupational HIV infection?; (2) What specific strategies are used to neutralize or overcome fear of HIV contagion?; (3) What factors and conditions are associated with this change? In-depth interviews will be carried out with 40 health care workers, who represent different health disciplines (e.g., medicine, nursing, dentistry), and who work in a variety of AIDS care facilities (e.g., clinics, hospitals, home care agencies). Health care workers can expect to care for increasing numbers of patients with HIV disease given current projections regarding the spread of the infection in the general population. Education to overcome fear of HIV contagion is essential if this important barrier to care (one of many) is to be removed. This innovative study should help generate a more grounded theory of AIDS education for health care professionals as well as demonstrate the relevance of employing rigorous qualitative methods in health services research.

Eisenberg, John M., MD, MBA, University of Pennsylvania, "Care-Giver Burden with AIDS," Grant No. HS 06640

This descriptive study seeks to identify and describe the patients with HIV infection who require informal care and the persons who are providing this care. The purpose is to measure caregiver burden and to determine the factors associated with increased caregiver burden. The caregivers studied are caring for patients from the Immunodeficiency Program Clinic of the Hospital of the University of Pennsylvania. Care-givers' perception of burden will be through the completion of a battery of instruments to measure his/her general health, social health, psychological well-being, financial costs of care, patient's level of disability, and caregiver's knowledge and attitudes about AIDS. Clinical variables will be obtained from chart review.

Epstein, Ronald M., M.D., University of Rochester, "Strategies for Improving Primary Care for HIV Patients" Grant No. HS 06444

The purpose of this study is to explore the motivations of primary care physicians who care for HIV-infected patients, the difficulties encountered by these physicians, and factors that enable them to overcome those difficulties. These issues include problems such as economic and time constraints, fear of contagion, and "burnout." In-depth interviews using a structured questionnaire will be administered to 30 primary care physicians who treat patients with HIV disease in six medium size cities. Information to be collected includes demographic and training information, descriptions of barriers and burnout. Both quantitative and qualitative ethnographic methods will be used. The results will be used to generate new hypotheses and to design interventions to increase the participation of physicians in the care of HIV-infected patients.

Gustafson, David H., Ph.D., University of Wisconsin, "Impact of Computer Support on HIV Infected," Grant No. HS 06177

This project will develop a computerized information and support services system for HIV-infected persons and evaluate the efficacy and cost-effectiveness of the system. The computer program is constructed to influence the health status, health resource utilization and risk behavior of infected individuals. This study is based in both Madison and Milwaukee, Wisconsin. The impact of CHESS (Comprehensive Health Enhancement Support System, the name of the computer based system) will be evaluated in a prospective, randomized controlled experiment. In some areas of the country, the demands of HIV infected patients for assistance are overwhelming both professional and volunteer sources of support. This is a potentially powerful new tool for HIV infected patients.

Hanley, Barbara, Ph.D., "HIV Home Healthcare Services: Survey and Policy Analysis," Grant No. HS 06404

The purpose of this study is to document the availability of services for HIV infected individuals, the number of people with HIV served, occurrence and reasons for refusal of service, types of services offered, and problems in delivering service as reported by the home healthcare aides in selected states. In addition, there will be a survey of the appropriate state agencies in those states to document state policies and plans regarding HIV, including, for example, reimbursement policies. A goal of the project is to provide baseline data to assist in health planning and policy decision. The study approaches the subject from two perspectives: 1) the official state agency perspective, and 2) the home health care agency perspective. Specific research questions have been formulated for each perspective. The study can provide important recommendations for improvements in home health care service delivery for HIV/AIDS persons and comparative data across states.

Phillips, Kathryn, M.P.A., Western Consortium of Public Health, "Government Intervention and Utilization of HIV Screening," Grant No. HS 06629 (dissertation)

This study is designed to examine how the use of HIV testing is influenced by local governmental policies regarding testing and care of AIDS patients. The study utilizes data obtained through the AIDS Knowledge and Attitude Survey Supplement from the National Health Interview Survey. The major research questions to be addressed include: 1) the influence of government intervention on screening use by exploring responses according to state regulations and funding on AIDS; 2) the relationship between government AIDS intervention in each state with specific characteristics of the state; 3) the comparability of HIV screening to other screening tools such as mammography and syphilis; and 4) the policy implications of these analyses. The potential findings of the project will contribute to the

knowledge base regarding testing, regulation and public policy related to HIV.

Ramsey, Paul, M.D., University of Washington, **"Primary Care of Patients With or At-risk for HIV,"** Grant No. HS 06454

The goal of this study is to assess the quality of care provided to patients with HIV infection. Primary care physicians, specifically family practitioners and internists, with varying degrees of experience and training in HIV infection will be studied. Interviews will be conducted with 140 primary care physicians from five northwestern states stratified by their experience with HIV-infected patients. Data will be collected on their knowledge of HIV infection, interviewing practices, and physical examination and counseling skills. The physicians' actual patients will also be interviewed for information on the quality and practice patterns. Multivariate analysis will be conducted to determine the relative importance of other physician-related and patient-related variables of care of HIV-infected patients. The results will permit an in-depth evaluation of the interaction between patient with or at-risk for HIV infection and primary care physicians. This information could be very useful in informing the design of medical education and continuing medical education curricula to improve the delivery of care to this population.

Ryan, John G., B.A., M.P.H., University of Texas Health Science Center, **"Is Family Medicine Meeting the HIV/AIDS Challenge?"** Grant No. HS 06615

This study will perform a mail survey of a national random sample of 2,500 board certified or eligible family physicians about knowledge, attitudes, and experiences concerning HIV/AIDS patients. The survey will be used to analyze these factors with regard to physician characteristics such as residency training, urban or rural setting,, and academic or private practice. The results will be made available to the American Academy of Family Physicians to encourage the development of an early care clinical protocol designed for family practice.

Safran, Charles, M.D., Beth Israel Hospital, **"Knowledge-Based Records for Patients with HIV Infection"** Grant No. HS 06288

The investigators propose to develop a knowledge-based medical record that will improve the quality and efficiency of care delivered to patients with HIV-related illness. The record system, known as KBMR-HIV, will provide reminders about deficiencies in care, follow-up and social service needs, and suggest cost-effective strategies for evaluating common medical problems in HIV patients. Integrating this system with ClinQuery (formerly known as PatientChase) will provide the physician with enhanced decision support by providing access to a data management tool which allows rapid exploration of a clinical database. In addition, access to selected medical literature

from the MEDLINE database will be available through PaperChase and on-line access will be provided to research protocols, results of decision and C/E analyses and clinical guidelines for management of HIV infection. The data will be stored in such a manner as to be of immediate use in patient care and also of value to future clinical, epidemiological or policy-oriented studies using aggregated longitudinal data. Patient information from KBMR-HIV will be transferred into a management database which will allow exploration by the user of an aggregate database built on information from patients treated in a variety of settings by a variety of practitioners. Patient confidentiality will be maintained by deleting any patient identifiers from the database and by tracking system users.

Scitovsky, Ann A., Palo Alto Medical Foundation, "Cost of Medical Care for HIV and Non-AIDS Patients," Grant No. HS 06646.

The principal aims of this study are (1) to provide detailed data on the use and costs of medical services of a group of persons infected with human immunodeficiency virus (HIV) who do not yet have AIDS as defined by the Centers for Disease Control (CDC); and (2) to explore the patient characteristics of these persons which may affect their use and costs of medical and support services over a given period of time. In addition, a smaller part of the study will compare the use and costs of medical services of patients with HIV-infections other than AIDS who participate in a drug trial with those of a matched group of persons on conventional treatment. This research will be a first step toward providing some basic data for estimating the use and costs of medical support services of persons infected with HIV from diagnosis to death, and will shed some insight on the use and costs of medical services resulting solely from drug trials.

Solomon, Liza, Johns Hopkins University, "Utilization and Insurance Among HIV Positive Drug Users," Grant No. HS 06441

This research involves a prospective study of the health services utilization and financing patterns for a population of intravenous drug users (IVDU's) with know HIV serologic status. The major objectives of the study include assessment of baseline patterns of health services utilization, analysis of the changes in utilization of these services and the relationship to progression of disease, investigation of the correlates of health services utilization and analysis of factors which influence changes in insurance coverage among HIV positive IVDU's. A cohort of 2,073 IVDU's have been recruited and screened thus far as part of an NIDA funded ongoing longitudinal study of the natural history of HIV infection among IVDU's (the ALIVE Study).

Turner, Barbara; Thomas Jefferson University, School of Medicine, "Consequences of Patterns of Provider Care for AIDS," Grant No. HS 06465

This project will examine specific patterns of outpatient provider care for AIDS patients of all ages who are New York or California Medicaid enrollees. Four groups of Medicaid enrollees will be studied: homosexual or intravenous drug user (IVDU) men, women, and children. A severity of illness index will be developed for children with AIDS following a similar process used for adults.

Publications on HIV Illness by Extramural Research Staff

- o Hellinger, Fred. "Updated Forecasts of the Costs of Medical Care for Persons with AIDS, 1989-93", AHCPR Program Note, January-February 1990, Vol. 105, No. 1.
- o Hellinger, Fred. "Forecasting the Number of AIDS Cases: An Analysis of Two Techniques", Inquiry, Volume 27, Fall 1990, pp.212-224.

General Health Services Intramural Research

The Division of Provider Studies is one of three major areas of policy research and analysis in AHCPR's Center for General Health Services Intramural Research. The Division of Provider Studies focuses on questions relating to the delivery of health care in short-term general hospitals in the United States. The various research studies undertaken by this program depend on two very large data bases that have been developed over the past decade to facilitate hospital-related policy research.

The first data base, the Hospital Cost and Utilization Project (HCUP), contains information on a sample of more than 500 hospitals. Included are 60 million summary abstracts of all patient discharges during two time periods, 1970-77 and 1980-87, characteristics of the institutions and the markets in which they operate, and background of the medical staff.

The second large data base, the State Hospital Data Project (SHDP), contains data on almost 15 million discharges from acute care hospitals in Maryland, New York, and Massachusetts from 1983 to the present and on the characteristics of those facilities.

Because of their size, these data bases provide the means to study even very rare medical events. Both the HCUP and SHDP data sets are being employed to study patients hospitalized for AIDS. For example, the relatively large number of AIDS cases included in the New York State data has provided the clinical information used to stage hospitalized AIDS patients by severity of illness. Such staging is essential to studies that compare different therapeutic approaches to treating AIDS patients or to compare costs of treatment across different hospitals and regions of the country. Both HCUP and SHDP data have been used to examine the costs and financing of inpatient care for AIDS taking into account differences in patient severity. These data will be used

in future studies of the epidemiology of AIDS, the variations in patterns of hospital treatments, and the factors responsible for differences between hospitals and regions with respect to the cost of diagnosis and treatment.

FY 1990 intramural research papers on AIDS from the Agency's Center for General Health Services Intramural Research:

Authors: Andrews, Roxanne, Keyes, Marge, Fanning, T, and Kizer, K.

Title: Lifetime Service Utilization and Expenditure Patterns for Medicaid Recipients with AIDS in New York and California.

Source: State Hospital Data Project

Authors: Andrews, Roxanne, Keyes, Marge, and Fanning, T.

Title: Annual Trends in Medicaid Expenditures and Service Utilization for AIDS in New York and California.

Source: State Hospital Data Project

Authors: Ball, Judy K., Farley, Dean E., and Turner, Barbara J.

Title: Does Familiarity Breed Effectiveness in the Treatment of AIDS Patients? Evidence from a National Sample of U.S. Hospitals.

Source: Hospital Cost and Utilization Project

Authors: Ball, Judy K., Kelly, Joyce V., Turner, Barbara J.

Title: Third-Party Financing for AIDS Hospitalizations in New York

Source: State Hospital Data Project

Authors: Rizzo, John, Marder, William, and Willke, Richard

Title: Physician Contact with and Attitudes Toward HIV-Seropositive Patients: Results from a Nation Survey.

Source: AMA Survey

Authors: Turner, Barbara J. and Ball, Judy K.

Title: Variations in Inpatient Mortality for AIDS in a National Sample of Hospitals.

Source: Hospital Cost and Utilization Project

Medical Treatment Effectiveness/Outcomes Research

The goal of the AHCPR's Medical Treatment Effectiveness Program (MEDTEP) is improved effectiveness and appropriateness of clinical practice. The Agency helps to generate scientific and policy-relevant information on the effectiveness of alternative strategies for the prevention, diagnosis, treatment, and

management of a wide variety of acute and chronic conditions. For example, clinical practice guidelines for AIDS and HIV infection will be developed through MEDTEP.

While almost all of the HIV/AIDS projects supported by the Agency are funded through the general health services research programs (extramural and intramural), in FY 1990, one AIDS-related research project was supported through the Agency's medical treatment effectiveness program:

Tosteson, Anna, Sc.D., Brigham and Women's Hospital,
"Cost-Effective Management of HIV-Related Illnesses," Grant No.
 HS 06694.

This project will develop models of the costs and quality of life gained from a broad range of strategies to care for HIV-infected patients with specific symptoms of central nervous system (CNS) disease.

**Development/Updating of Clinical Guidelines,
 Quality Standards, Performance Measures,
 and Medical Review Criteria**

AHCPR promotes the quality, appropriateness, and effectiveness of health care by facilitating the development, review, and updating of clinically relevant guidelines for specific conditions. Health care providers, educators and consumers will use these guidelines to help determine how to prevent, diagnose, treat and manage health conditions most effectively. The Agency also assists in the creation and periodic updating of quality standards, performance measures and medical review criteria that may be used to assess and help ensure the quality of health care. Under P.L. 101-239, two mechanisms may be used to accomplish these: (1) panels of qualified experts and health care consumers can be convened, and (2) contracts can be issued to public and non-profit private organizations. AHCPR elected to utilize the panel process for developing the initial seven guidelines in FY 1990 and 1991.

The priorities of clinical conditions to be studied are identified in conjunction with the Institute of Medicine, the Health Care Financing Administration and professional organizations. Criteria for the selection of conditions include:

- specific needs of the Medicare and Medicaid populations;
- expected potential for reducing inappropriate variations in the prevention, diagnosis, management or outcome of a particular condition;
- number of individuals affected by the clinical condition;

- cost of the condition to all payers including patients;
and
- adequacy of scientific evidence to develop guidelines
and standards, etc.

The AHCPR is convening in FY 1991 a panel of experts and health consumers to develop a series of clinical practice guidelines for AIDS and HIV infection. These guidelines will be completed in FY 1992. Standards of quality, performance measures and review criteria will be developed thereafter.

HEALTH CARE FINANCING ADMINISTRATION

ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)Part I - Background

In fiscal year 1991, HCFA expects to spend about \$1 billion in Federal Medicaid and Medicare funds for the care and treatment of persons living with AIDS (PLWA) and those infected with the human immunodeficiency virus (HIV). Combined Federal and State Medicaid expenditures for AIDS-related care in FY 1991 are estimated at \$1.7 billion, or nearly 2 percent of Medicaid's total payments. These outlays are projected to reach \$2.5 billion for FY 1993. Medicare pays from 1 to 2 percent of the cost of direct care for PLWAs.

Medicaid pays about 25 percent of the aggregate cost of medical care for these populations, more than any other single payer. Nationally, Medicaid serves at least 40 percent of all AIDS patients and up to 90 percent of all children with AIDS. These figures vary considerably from State to State. Recent trends indicate substantial rates of increase in reported cases from small cities and rural areas and among populations of special concern to Medicaid (i.e., pregnant women, infants, and children).

HCFA policy requires that AIDS be addressed as any other serious illness. While HCFA offers States maximum flexibility to meet local needs and assure broad access to care, it also encourages the private sector and voluntary organizations, as well as AIDS patients themselves, to share responsibility for related health care costs. HCFA promotes coordination of multiple funding sources in financing services for PLWAs.

PLWAs generally become eligible for Medicaid as members of the following groups: low-income individuals receiving Aid to Families with Dependent Children or Supplemental Security Income; pregnant women and children under age 6 in families with incomes below 133 percent of the Federal poverty level; and, at State option, low-income people who qualify as medically needy. A single adult who is not pregnant or a childless couple between the ages of 22 and 64 cannot become eligible for Medicaid without a disability.

States serve Medicaid eligible PLWAs within existing programs or use Federal waiver authority to provide cost-effective service delivery. State Medicaid programs must cover certain services, including inpatient and outpatient hospital care, early and periodic screening, diagnostic and treatment (EPSDT) services, and physician care. Other Medicaid AIDS-related services covered

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at State option include targeted case management and hospice services. Alabama, Maryland, Pennsylvania, and Washington State provide targeted case management services for Medicaid eligible persons with human immunodeficiency virus (HIV) infection or AIDS.

All States now cover zidovudine (AZT) and other appropriate drug therapies. Several States also pay premiums to continue the employer-based health insurance policies of PLWAs as part of a broader group of Medicaid-eligible individuals, when it is cost-effective to do so.

HCFA's home- and community-based services waivers allow States to provide services (other than room and board) not otherwise available under the State Medicaid plan. HCFA has approved AIDS home- and community-based services waivers for 12 States: California, Florida, Hawaii, Illinois, Missouri, New Jersey, New Mexico, Ohio, Pennsylvania, South Carolina, Virginia, and Washington. In addition, North Carolina and Illinois include PLWAs under waivers developed for broader disabled populations.

States can also opt to enhance Medicaid access to services by increasing payments to providers. Twelve States offer enhanced payment to nursing homes for AIDS-related care. New York has developed a system of designated care centers providing or arranging for a full range of care, including housing, home health care, and hospice services for persons with AIDS. Covered services provided by these centers qualify for higher Medicaid reimbursement.

Discrimination against persons with AIDS and HIV infection is illegal under Federal law. Regional office staff from HCFA, the Office for Civil Rights, and other HHS agencies have obtained nursing home admission for Medicaid eligible PLWAs who experienced discrimination.

AIDS coordinators in each of HCFA's 10 regional offices exchange information and work with State Medicaid staff to make their Medicaid programs as flexible and comprehensive as possible. These coordinators meet with their regional counterparts in other Federal agencies to help States eliminate obstacles that hamper access to services and financing, and to plan regional AIDS conferences for State staff.

HCFA works with other Federal agencies at the national level to keep abreast of new developments in AIDS treatments, to share data on the disease, and to coordinate programs. HCFA health services research grants also add to the pool of knowledge about the use of services and expenditures associated with HIV infection and AIDS.

Part II - Program Data

States do not report Medicaid expenditures by diagnosis category, nor do Medicare contractors capture data in this manner. HCFA actuaries estimate Medicaid and Medicare AIDS-related costs and numbers of individuals as follows:

Fiscal Yr:	FY86	FY87	FY88	FY89	FY90	FY91	FY92	FY93
PROGRAM COSTS (\$millions)								
MEDICAID								
Federal	110	200	330	490	670	870	1,080	1,290
State	110	190	310	460	630	820	1,020	1,220
Total	220	390	640	950	1,300	1,690	2,100	2,510
AIDS AS A PERCENT OF FEDERAL MEDICAID BUDGET								
Fed MCD ¹ Tot	23,500	26,590	29,010	32,680	38,989	48,794	56,713	64,855
AIDS %	0.5%	0.8%	1.1%	1.5%	1.8%	1.8%	2.0%	2.0%
MEDICARE	5	15	30	55	110	180	280	385
AVERAGE NO. OF INDIVIDUALS COVERED								
MEDICAID	5,300	8,600	13,500	20,400	27,700	35,300	42,800	50,000
MEDICARE	100	300	700	1,300	2,100	3,100	4,300	5,600

¹(MCD) - Medicaid

ALZHEIMER DISEASE
Obligations

	1988 <u>Actual</u>	1989 <u>Actual</u>	1990 <u>Actual</u>	1991 <u>Estimate</u>	1992 <u>Estimate</u>
Public Health Service:					
<u>National Institutes of Health:</u>					
National Institute on Aging.....	\$47,734,000	\$77,729,000	\$93,995,000	\$155,000,000	\$162,750,000
National Cancer Institute.....	---	106,000	84,000	86,000	87,000
National Heart, Lung, and Blood Institute.....	---	---	348,000	360,000	380,000
National Institute of Dental Research.	---	---	321,000	343,000	361,000
National Institute of Neurological Disorders and Stroke.....	18,779,000	20,990,000	21,096,000	34,546,000	36,964,000
National Institute of Allergy and Infectious Diseases.	1,041,000	1,539,000	1,861,000	2,014,000	2,196,000
National Institute of Child Health and Human Development...	671,000	741,000	615,000	650,000	700,000
National Institute of Environmental Health Sciences.....	575,000	595,000	387,000	400,000	416,000
National Institute on Deafness and Other Communication Disorders.....	---	---	857,000	947,000	1,034,000
National Center for Research Resources.....	1,211,000	1,429,000	1,158,000	1,110,000	1,010,000
National Center for Nursing Research....	230,000	1,853,000	2,242,000	2,700,000	3,000,000
Office of the Director, NIH.....1/	66,000	---	104,000	109,000	114,000
TOTAL, NIH.....	70,307,000	104,982,000	123,068,000	198,265,000	209,012,000

	1988 <u>Actual</u>	1989 <u>Actual</u>	1990 <u>Actual</u>	1991 <u>Estimate</u>	1992 <u>Estimate</u>
<u>Centers for</u> <u>Disease Control</u>	104,000	155,000	156,000	175,000	200,000
<u>Alcohol, Drug</u> <u>Abuse and Mental</u> <u>Health</u>					
<u>Administration</u>	14,031,000	23,632,000	23,695,000	30,774,000	32,277,000
TOTAL, PHS.....	84,442,000	128,769,000	146,919,000	229,214,000	241,489,000
<u>Health Care</u> <u>Financing</u>					
<u>Administration..</u>	78,000	1,100,000	2/	2/	2/
<u>Office of Human</u> <u>Development</u>					
Administration on					
Aging	1,900,000	470,000	350,000	1,000,000	1,000,000
TOTAL, DHHS....	86,420,000	130,339,000	147,269,000	230,214,000	242,489,000

1/ This includes AREA awards for FY 1988 - 1992, and RCMI awards for FY 1988.

2/ Health Care Financing Administration obligations are not available.

ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION

Alzheimer's Disease

National Institute of Mental Health

The prevalence of this drastic, debilitating disorder is rapidly escalating along with a corresponding increase in the burden Alzheimer's disease places upon society. Best estimates indicate that at least 4 million Americans presently suffer from Alzheimer's disease or related dementias. However, a study from Boston, with wider criteria than other studies, suggests that rates of dementia are higher and a higher proportion of all cases of dementia is Alzheimer's disease. The risk of developing Alzheimer's disease escalates dramatically with age--the latest estimates are that roughly 25 percent of those 85 or older have the disease.

Alzheimer's disease tends to take hold slowly and can last 20 years or more. The first stage is characterized by the victims' loss of recent memory; the second, by growing memory loss, confusion, a shorter attention span and behavioral problems such as irritability, suspiciousness and restlessness; the third, preceding death, by victims' inability to recognize themselves and others, to talk or control other basic functions.

Alzheimer's disease victims have a specific set of symptoms, but a definitive diagnosis is now possible only by examination of brain tissue after death. The changes that are the hallmarks of the disease are: cell loss; neurofibrillary tangle, an abnormal nerve cell body filled with masses of twisted proteins; and neuritic plaque, a focal collection of degenerating nerve endings surrounding a core of "amyloid" protein. Cell loss, tangles and plaques occur primarily in brain regions associated with higher cognitive functions; i.e., learning and memory. But the same pathology that characterizes Alzheimer's disease is also seen, to a lesser extent, in normal aged brain tissue.

The disease is most likely caused by genetic, environmental, immunologic and/or metabolic factors. Some researchers in genetic linkage analysis also have proposed a multi-gene model of Alzheimer's. Depression sometimes mimics the symptoms of early Alzheimer's disease, and this complicates the clinical picture. The burdens of Alzheimer's disease to family members of the victim are becoming better understood. Stress associated with family-based care of the elderly has significant emotional and health consequences. Research on the primary caregiver, who is generally a spouse or daughter, has documented an array of psychological and emotional burdens. Dr. Linda Teri at the University of Washington has found depression in over half of the caregivers of depressed Alzheimer's disease patients.

The cost of caring for individuals with Alzheimer's disease and related dementias has been conservatively estimated to be \$38 billion to \$42 billion per year, for direct costs alone. The need for appropriate services and high-quality care will grow, especially since effective methods of prevention and cure are unknown at the present time.

Accomplishments

A Protein Found Only In Alzheimer's Disease Patients May Allow For Accurate Diagnostic Testing

At Albert Einstein College of Medicine, Dr. Peter Davies has discovered an abnormal protein, called A-68, in the brains of patients with Alzheimer's disease. This discovery may ultimately lead to a clinically useful diagnostic test for this disorder. Using a monoclonal antibody the researcher found that the antibody identifies the abnormal Alzheimer's disease associated protein in 85 percent of patients. The A-68 protein is not correlated with severity of clinical dementia, neuritic plaques, or old age per se. Research is continuing to determine whether the protein can be reliably assessed in the blood or cerebrospinal fluid of living patients.

Possibility Of Medication To Relieve Cell Loss

Charles B. Nemeroff and colleagues at Duke University are investigating the dynamic state of brain cholinergic neurons by measuring markers of neuronal integrity, neuronal activity, receptor number and function. Results, thus far, provide evidence of complete loss of ability by specific brain neurons to take up the precursor of acetylcholine, and an increased uptake of this precursor by the remaining cholinergic neurons in some brain areas. These results support the view that Alzheimer's disease involves neuronal metabolic dysfunction, as well as actual loss of neurons, and that in some brain regions the remaining neurons attempt to compensate by increasing transmitter production. These findings are significant since they point to the possibility of pharmacological manipulation to lessen the impact of cholinergic cell loss.

Two-Drug Combination Therapy

NIMH intramural scientists are developing new strategies to delay progression of symptoms of Alzheimer's disease. Previous work showed that the monoamine oxidase inhibitor, L-deprenyl, which delays symptoms of Parkinson's disease, was helpful in the symptomatic treatment of Alzheimer's disease. Long term investigations are underway to evaluate the possible neuro-protective effects of L-deprenyl. In an effort to expand the horizon of dementia therapies, the approach of combining different pharmacologic agents (e.g. physostigmine with L-deprenyl) is now increasingly being used in studies. Such combination approaches may prove to be the dominant therapeutic strategy in Alzheimer's disease for the 1990s.

Specific Cognitive Deficits Matched To Progressive Brain Disorders

The affects of Alzheimer's disease on speech and memory has led Dr. Kathryn Bayles at the University of Arizona to develop a series of sensitive communication disorder tests that demonstrate that even mildly affected Alzheimer's patients perform significantly more poorly than controls. Dr. Bayles has also devised a series of evaluations for late-stage Alzheimer's patients. Previously, the severe cognitive impairment of such individuals led them to be considered untestable. Dr. Bayles has found considerable variation in communication function. Mechanics of word reading and writing from dictation are easier and less affected than naming. These results yield the first indication of the relative difficulty experienced by Alzheimer's patients in performing common tasks.

Current Activities

Genetics

Today, genetic inheritance is the only etiologic factor identified for Alzheimer's disease, and thus the only confirmed clue to uncovering the mystery of the disease.

In earlier NIMH-supported research, Dr. Leonard Heston at the University of Minnesota discovered a remarkable etiologic clue to Alzheimer's disease in the form of an association with Down's syndrome. Individuals with Down's syndrome achieving 40 years of age develop symptoms similar to Alzheimer's disease. These similarities extend to enzymatic changes and the anatomical distribution of brain lesions. A second link between the two conditions has also been confirmed, wherein a significant excess of Down's syndrome births were found in families identified by a case of Alzheimer's disease. Other investigators subsequently located, on chromosome 21, the chromosome locus of Down's syndrome and genetic markers both for familial Alzheimer's disease and for the precursor of the abnormal amyloid protein found in brain plaques. Despite initial hopes that the two genes might be more closely linked, the most recent molecular studies have shown that the marker gene for familial Alzheimer's disease and the gene for amyloid protein reside at separate points on chromosome 21.

A linkage analysis study is now underway as a result of finding increased membrane fluidity in blood platelets in Alzheimer's patients. This abnormality is hypothesized to be a product of the Alzheimer's disease gene. There is now evidence that this membrane abnormality identifies a subgroup of patients with distinct clinical features--including an earlier symptomatic onset, a more rapidly progressive decline, and greater likelihood of a family history of dementia--and that it appears to be a stable, familial trait vertically transmitted in families through inheritance of a highly penetrant autosomal gene. Following the discovery that the genetic locus for this trait may reside on the long-arm of chromosome 21, linkage analysis is being used to

determine definitively whether the trait is located in this region or closer to a region associated with Down's syndrome, and whether it is distinct from the genes for familial Alzheimer's disease and the amyloid precursor protein. Further investigations are needed to determine the sensitivity and specificity of platelet membrane fluidity relative to Alzheimer's disease before its practical usefulness as a diagnostic marker for Alzheimer's disease can be determined.

As part of a larger initiative on the genetics of mental illness (The Diagnostic Centers for Psychiatric Linkage Studies), NIMH funded three sites (Harvard University, Johns Hopkins University, and the University of Alabama at Birmingham) to focus efforts on genetic research in Alzheimer's disease. The primary goal of the initiative is to establish a national resource of immortalized cell lines and clinical data from reliably diagnosed index cases and key relatives. Participants in this program are collaborating in developing a common protocol detailing diagnostic tools for both patients and relatives, determining appropriate small-family configurations and pedigree extensions rules for future linkage studies, and evaluating reliability of assessments. It is anticipated that one or more subsequent Request for Applications will be issued to support genetic analyses of the cells, and appropriate statistical analyses will be conducted to detect linkages as well as to test for hypothesized genetic heterogeneity.

This work will add to the ongoing investigation at the University of Minnesota that is establishing lymphoblastic cell lines on families affected by autopsy-proven diagnoses of Alzheimer's disease. Such tissue samples will be a permanent source of DNA, allowing characterization of the DNA sequences critical in Alzheimer's disease. NIMH has also been working with the National Institute on Aging to coordinate the efforts of their respective Alzheimer's gene bank initiatives, and will continue to encourage collaboration between their investigators to ensure the comparability of results despite differences in study designs.

Neuroscience Of Alzheimer's Disease

Both the mechanisms of brain aging and the neuropathology of age-related brain diseases are of enormous importance to the ability to differentiate normal aging from Alzheimer's disease and other dementias. In a new project, investigators in the NIMH Intramural Laboratory of Clinical Science are working to develop a human cell culture model suitable for studying Alzheimer's disease and other neuropsychiatric disorders. Cultures of proliferating human olfactory neurons (responsible for the sense of smell) have been established. The anatomic and functional characteristics of these cells are under investigation.

Dr. Carol Miller at the University of Southern California has identified different localized networks of neurons which are distinctively affected in Alzheimer's disease. Her results

reveal an unfolding, systematic course of changes from one to sixteen years after diagnosis. She has also discovered selective optic nerve degeneration and retinal abnormalities that suggest that the neurofibrillary tangles frequently found in the brains of Alzheimer's patients may not be required for cell death. Dr. Miller's studies are now comparing the neuronal changes found in Alzheimer's disease with those in other dementing diseases, such as Pick's and Parkinson's to help distinguish any changes that are specific to Alzheimer's disease.

Understanding basic mechanisms of memory function is critical for understanding the mechanics of Alzheimer's disease. The hippocampus, an important brain structure for memory storage, is severely affected in Alzheimer's disease. Research by Dr. Carl Cotman at the University of California, Irvine, suggests that it is possible to re-grow neuronal connections that have been severed in the hippocampus. Work is continuing on this promising finding which may make it possible to restore memory loss.

Neurochemical Regulation Of Memory

Dr. Michela Gallagher at the University of North Carolina is studying the neurochemical regulation of memory through an investigation of the status of cholinergic and peptidergic function and a range of behavioral parameters in the aged rat. Early detection of age-related impairments can be accomplished using tests of spatial learning, sensorimotor function, and circadian pattern of water intake. Biochemical studies show impairment in spatial learning to be proportional to increases in dynorphin (a peptide) levels in the hippocampus of aged rats. This work may have implications for mild cognitive impairments in normal human aging and emergence of dementia in Alzheimer's disease.

Neurotransmitter Studies May Lead To Medications

Several grantees are studying chemical neurotransmission abnormalities in the brains of Alzheimer's patients. Since loss of neurons that communicate via acetylcholine and acetylcholine depletion are almost always observed in the brains of those who have died from Alzheimer's disease, studies of this neurotransmitter have direct implications for understanding the disease. Dr. Paul Newhouse of the University of Vermont is employing a series of pharmacological probes to investigate how loss of brain cells and receptors correlates with cognitive deficits. By exploring the effects of a nicotine antagonist, mecamylamine, Dr. Newhouse hopes to determine whether the cognitive and behavioral deficits of Alzheimer's disease can be prevented.

A naturally occurring chemical, cholinesterase, is suspected to cause depletion of acetylcholine. Investigators at Southern Illinois University are now conducting a clinical trial of metrifonate, a chemical which was found to inhibit the production of cholinesterase as much as 80 percent, in a previous study with Alzheimer's patients. Cognitive performance in these patients

was improved according to various assessments, including reports by family members.

Many NIMH studies are increasing our knowledge of the mechanisms of neuronal communication and the multiplicity of chemical messengers available to nerve cells. Evidence has shown that a multi-faceted approach to the study of these chemical messengers is necessary for the development of medications to treat Alzheimer's disease.

Diagnostic Efforts In Alzheimer's Disease And Depression

Scientists in the Intramural Program are focussing on the frequent overlap of symptoms in depressed and demented patients. A diversity of methods is being used to test both Alzheimer's disease and depressed patients. Some of these measures, which include cerebrospinal fluid markers, urine metabolites, neuroendocrine responses, brain imaging techniques, neuropsychological cognitive testing, mood rating, and daily activities assessment, are capable of distinguishing demented from depressed patients. However some of these measures show remarkable similarities among diagnostic groups, suggesting biological as well as clinical overlap between depression and dementia.

Another Intramural research group headed by Dr. Trey Sunderland has developed, and are continuing to test, a Dementia Mood Assessment Scale, designed specifically to rate mood in language-forgetful and sometimes entirely nonverbal Alzheimer's patients. This scale is helpful in tracking the variable mood states of dementia patients over the course of their illness, and may provide clues as to when antidepressant treatment may be indicated for these patients.

Dr. Patricia Prinz at the University of Washington is using EEG activity as a marker to discriminate mild dementia from normal aging and from elderly depression. She has been able to correctly classify 85 percent of normal aged from mildly demented subjects. Because the accuracy of formulating a differential diagnosis in the earliest stages of the disease has heretofore been so poor, and has been a major obstacle to treatment and longitudinal studies of the course of the illness, Dr. Prinz's finding represents a significant development.

Another non-invasive approach to diagnosis is using EEG sleep patterns, in particular rapid eye movements (REM). Dr. Charles Reynolds at the Western Psychiatric Institute and Clinic in Pittsburgh has found differences in REM activity among diagnostic groups. Both depressed and demented patients are distinguishable on the basis of his REM test from healthy controls. Longitudinal studies are ongoing in groups who are being followed to clarify relationships between persistent sleep abnormalities, pathogenesis, and illness course.

Assessment Of Cognitive And Motor Deterioration

The NIMH intramural Laboratory of Clinical Science is developing non-invasive procedures to identify patterns of cognitive deficit, to provide tools for accurately assessing cognitive change after pharmacologic intervention, and, most importantly, to test and develop models of normal cognitive functioning based on how such functions and systems break down following brain damage and disease. Results of recent studies of semantic memory, object recognition, spatial memory and visual attention by Dr. Martin and colleagues have suggested that Alzheimer's patients suffer from a disorganization or an actual loss of the specific types of knowledge that normally allow people to name objects. Ongoing studies are attempting to determine the extent to which these problems represent actual loss of knowledge and skill versus impaired access to relatively intact stores of information. Specified variations in the patterns of cognitive deficit in different Alzheimer's patients have been identified and may be helpful. Also under investigation is the question of whether normal learning of different types of information can be demonstrated in these patients using procedures that do not require conscious awareness of the learning event, and the relation between this type of learning and clinically-relevant cognitive deficits. Additional studies focus on patterns of attention and memory dysfunction in Alzheimer's patients and elderly depressed individuals.

Using multiple brain imaging techniques, Drs. Alan Kluger and Mory DeLeon of New York University are investigating the connections among cognitive impairment, motor dysfunction and white matter brain lesions. Their previous research found a decreased density of white matter in the brains of Alzheimer's patients. The Alzheimer's patients also have consistent and significant decreases in brain metabolism. Their current longitudinal research is testing the hypothesis that both Alzheimer's patients and normal elderly with white matter changes are at greater risk for cognitive/motor deterioration over time. Although these changes may be independent of Alzheimer's disease, they may add significantly to the brain-damage burden of the patient.

Another challenge to accurate assessment of cognitive function is the literacy level presumed by the testing instruments. Dr. Ramon Valle of San Diego State university has translated into Spanish and is validating for use with older Hispanics, two commonly used cognitive screening instruments: the Mini Mental Status Exam and the Blessed-Roth Dementia Scale. Dr. Valle has found that the Hispanic versions of these screening measures are valid with literate Hispanics but inadequate for the assessment of dementia in poorly educated individuals. This project addresses the need for culturally and educationally fair cognitive assessment devices for at least one segment of the growing ethnic minority elderly population.

Depression And Behavior Problems Complicate The Clinical Picture

Not only is it difficult to diagnostically separate Alzheimer's disease from depression in the elderly, but many patients with Alzheimer's develop the added hardship of depression. Dr. Linda Teri of the University of Washington has implemented a behavioral treatment for depression by training family members in skills designed to decrease depression. One of the skills is to identify suitable pleasant activities and then engage the Alzheimer's disease patient in participation to improve mood as well as the interpersonal relationship between the patient and caregiver. It is noteworthy that depression was observed in over half of the caregivers of depressed Alzheimer's disease patients at the time they entered this study, suggesting that the task of dealing with both Alzheimer's disease and depression in the patient may put caregivers, themselves, at risk for depression.

Behavioral disturbances are frequently another complication of disease patients. When Alzheimer's patients manifest psychosis or agitation they are most often treated with neuroleptic medications--the same antipsychotic treatments used with psychiatric patients who suffer from hallucinations and delusions. A problem with neuroleptics is the risk of tardive dyskinesia (a condition characterized by involuntary jerky movements). Dr. Davangere Devanand at Columbia University is addressing the lack of adequate data on the effects and safety of neuroleptic medications used to treat these conditions in Alzheimer's patients. His study is assessing the efficacy and side effects of a traditional dose of oral haloperidol versus a low dose on: symptoms, activities of daily living and cognitive functioning.

Dr. Barry Rovner of Johns Hopkins University is implementing an intervention designed to reduce behavioral problems among demented patients in nursing homes. This randomized controlled clinical trial involves three components: 1) multi-disciplinary clinical visits directed by a psychiatrist; 2) administration of appropriate psychotropic drugs; and 3) an activities program designed just for the demented patients. This study has implications not only for Alzheimer's disease patients, but also for systems of care.

The Family

There is continuing evidence that the stress of caregiving is associated with health consequences. NIMH has placed particular emphasis on the area of family studies, and for several years has had in force an announcement soliciting grant applications for "Research on Family Stress and the Care of Alzheimer's Disease Victims."

NIMH is funding several projects focussing on the chronic impact of caregiving and the relationships between psychological distress and physical health. Previous results from Drs. Janice Kiecolt-Glaser and Ronald Glaser at Ohio State University, indicated that family caregivers of Alzheimer's disease patients

not only have increased rates of infectious illness and symptoms of clinical depression, but often suffer suppression of their immune systems. Ongoing studies are exploring how caregivers in different contexts--those caring for the patient at home, those caring for a patient in an institution, those who are recently bereaved--vary in immune function. Dr. Igor Grant at the University of California, San Diego is investigating whether neuroendocrine and immunologic variables may help distinguish successful from unsuccessful caregivers. This may help predict those who will themselves develop an illness.

At the Palo Alto Veterans Administration Medical Center, Dr. Dolores Gallagher is studying caregivers and has found the rate of anger reported was 67 percent, with depressed mood identified in 54 percent of caregivers. Dr. Gallagher has developed two interventions--one aimed at anger management and the other at depression. Pilot data show that the anger management intervention may be particularly effective in reducing clinical symptoms in caregivers. Researchers are also assessing the hypothesis that individuals who tend to hold their anger in may be at greater risk of experiencing cardiovascular disease.

An incidental finding from a study of neurotransmitter concentrations in the cerebrospinal fluid of Alzheimer's patients and controls demonstrated dramatic elevations of GABA (gamma-aminobutyric acid) in a segment of the control group --chronically stressed, yet well functioning, caregiver spouses. Dr. Nunzio Pomara of the Nathan Kline Institute and New York University found no concomitant increase in markers for other neurotransmitters such as dopamine, serotonin or norepinephrine. The meaning of these findings is unclear, and further research is called for to replicate the results and to determine the implications of the GABA elevations.

Dr. Leonard Pearlin at the University of California, San Francisco, is attempting to identify the range of stressors experienced by caregivers in conjunction with their access to and use of formal and informal supports. In another study, caregiving "careers" are being followed, in which new caregivers will be studied until death of the care recipients. Drs. Powell Lawton, Rachel Pruchno, and Ms. Elaine Brody, of the Philadelphia Geriatric Center, will study these careers for the impact of family dynamics, length of caregiving, and personal characteristics of the caregivers. Another factor being assessed is daughter's marital status in a subgroup of caregiving daughters of widowed, impaired older parents.

Services Research And Systems Of Care

NIMH continues to solicit grant applications on "Mental Illness in Nursing Homes." Projects currently funded include attention to such issues as work stress and morale of nursing home employees, and the effect of staff expectations on residents' functional status. The care of the elderly residing in personal care homes, a type of facility where increasingly many mentally

ill elderly are found, is being examined at the Community Services Institute in Narberth, Pennsylvania. Personal care homes have not traditionally provided mental health care, and Dr. Leonard Gottesman is studying strategies for improving care of mentally ill residents of such homes, as well as their cost effectiveness, since these facilities are replacing large state hospitals as homes for the mentally ill.

A currently funded service demonstration project is evaluating the effectiveness of providing trained respite care workers to caregiving families of Alzheimer's disease patients, in terms of both improvements in the families' quality of life and reductions in the patients' institutionalization rates. Another project is evaluating a model program for elderly persons disabled with Alzheimer's disease or other chronic mental disease, which encompasses individual assessment and treatment planning, case management, and supported referral. Patients in the program are being compared with controls in terms of their functioning, maintenance of residence in natural community settings, services utilization, mortality and morbidity rates, and quality of life.

Training Of Research And Clinical Personnel

NIMH has developed a Research Teacher/Investigator award program called the Geriatric Mental Health Academic Award program, with 10 awards presently being supported for seven psychiatrists and three nurses. In addition, two young investigators are supported by Research Scientist Development Awards in their study of the etiology, pathogenesis and diagnosis of Alzheimer's disease. NIMH also supports a three-part clinical training program in Mental Health and Aging which focuses a portion of the curricula on Alzheimer's disease. Sixteen awards to various mental health disciplines are presently being funded: 4 individual faculty scholar awards, 4 institutional clinical training grants for minority students, and 8 institutional clinical training grants for general training.

Educational Materials And Information Dissemination

NIMH has an active information dissemination program on Alzheimer's disease. Efforts include distribution of the Fact Sheet on Alzheimer's Disease written especially for families, and dissemination of research findings to the field. The Fact Sheet has recently been updated, and the new version is now available.

In March 1990, NIMH held a workshop on the "Mental Health of Family Caregivers in Alzheimer's Disease and related Dementias," in which leading researchers discussed current findings and future research needs regarding the interaction between physical and mental health in Alzheimer's disease caregivers, intervention strategies with families of Alzheimer's disease patients, and mental health services that take cognizance of family issues in Alzheimer's disease. A forthcoming volume based on this workshop will further define and foster new directions in services research on Alzheimer's disease.

Papers from a 1989 NIMH conference on "Age and the Organic Syndrome of Delirium" are also being prepared for publication. At this conference, investigators and clinicians discussed advances in assessing and understanding states of delirium in the elderly, identified current research needs, and considered changes in diagnostic nomenclature that may assist in improving medical diagnosis and treatment of states of delirium. Syndromes of delirium are frequently superimposed on demented patients's basic cognitive deficits, and often reflect underlying conditions that tend to be life-threatening, such as concurrent medical disorders or pharmacological toxicity.

The Future

Council And Advisory Panel On Alzheimer's Disease

NIMH currently provides the Deputy Executive Secretary and staff support for the Department of Health and Human Services' Council on Alzheimer's Disease and the Advisory Panel on Alzheimer's Disease, both of which were established by P.L. 99-660. The Council is composed of Federal employees, while the Panel is a non-Federal advisory body appointed by the Office of Technology Assessment. The Council coordinates basic research on brain and behavior, epidemiology, diagnosis, treatment, costs, and financing and is charged with the responsibility for an annual report to Congress detailing progress in basic and clinical research on Alzheimer's disease. In 1990, the Council also assembled and distributed a detailed compilation of all the research projects, demonstrations and other activities on Alzheimer's disease and related dementias funded by its member agencies.

The Advisory Panel in 1989 published its first of four Congressionally mandated reports, in which it set forth recommendations for legislative and administrative actions to improve services for patients with Alzheimer's disease and related dementias and their families. It also set forth recommendations on how to provide for promising biomedical research on this disease. The Panel's second report updates topics covered in the earlier report, such as biomedical and services-oriented Alzheimer's disease research, financing of care, and eligibility for services, and addresses the special topics of personnel and training issues in the care of Alzheimer's disease victims.

As a major emphasis of its "Decade of the Brain" programs, NIMH will stimulate additional research on Alzheimer's disease in an effort to answer many of the puzzling questions surrounding the disease and to determine the best treatments and services possible. Future directions of Alzheimer's disease research at NIMH include: 1) the molecular genetics of Alzheimer's disease; 2) biochemical analyses of the neuropathological characteristics that define Alzheimer's disease--neurofibrillary tangles and amyloid plaques; 3) the role of nerve growth factors in Alzheimer's disease and the potential use of neural implants as a

research tool; 4) identification of diagnostic markers for Alzheimer's disease --particularly markers useful at early stages of the disease--including peripheral biological markers, and/or behavioral, electrophysiological, or radiological indices; 5) further investigation with brain imaging techniques, such as positron emission tomography (PET) and magnetic resonance imaging (MRI), to study changes in brain structure and metabolism in Alzheimer's patients; 6) refinement of diagnostic procedures for Alzheimer's disease; 7) improved understanding of the pathogenesis and course of psychiatric and behavioral symptoms in Alzheimer's disease; and 8) evaluation of strategies for clinical intervention in Alzheimer's disease, including behavioral and psychopharmacological techniques for managing symptoms or arresting cognitive decline, and interventions and services for supporting family members and alleviating caregivers' stress.

CENTERS FOR DISEASE CONTROL
CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION

Alzheimer's Disease

Alzheimer's Disease and Related Disorders

Dementias are among the most common neurological problems. It is estimated that 1.5 million Americans have severe dementia in which someone else must care for them, and an additional 1-5 million Americans have mild or moderate dementia. Projections over the next 50 years are that the number of Americans with severe dementia may increase five fold. Alzheimer's disease (AD), the most common cause of dementia, has been the focus of considerable research in recent years. The understanding of the genetics, pathophysiology, and diagnosis of AD has increased in recent years, but knowledge of its epidemiology and treatment is scant. In 1990, CDC gathered a group of independent consultants with expertise in neurology, epidemiology, and public health practice to provide expert opinions on the direction for future research and programmatic activities for dementia.

At present, CDC is contributing to progress in AD and related disorders through the following:

o Assisting States with Surveillance of Dementias

The surveillance of dementias has a variety of difficulties due to the lack of simple, operational, diagnostic criteria and to incomplete case finding. The CDC is cooperating with several States in improving surveillance for the dementias. In February 1990, CDC published a report concerning the surveillance efforts of the Alzheimer's Disease Program of the California Department of Human Services. In the future, repeated surveys of persons 65 and older to examine cognitive impairment or autopsy studies to examine pathologic changes in the brain may be helpful in assessing the completeness of surveillance and thus the public health burden of Alzheimer's disease.

o Explaining Increased Mortality Rates Due to AD

In November 1990, CDC reported that the age-adjusted mortality rate for Alzheimer's disease as the underlying cause of death increased 950 percent in recent years (from 0.4 per 100,000 in 1979 to 4.2 per 100,000 persons in 1987). The reasons for this increase are not clear, but may be due to increased awareness of AD and related disorders causing death certificates to be more sensitive or less specific for the diagnosis of AD during life. To examine this hypothesis, CDC is further analyzing national mortality and morbidity data. In addition, CDC is supporting a study of death certificate coding over time for decedents who had dementia.

o Planning for the Needs of Professionals and Caregivers

A survey of various caretaking arrangements other than institutionalization is being planned. The purpose of the study

will be to determine the status of caretaking arrangements on medical and social outcomes, especially institutionalization. An additional study will focus on the effects of caring for a dementia patient on family members, including caregivers.

CENTERS FOR DISEASE CONTROL

National Center for Health Statistics

ALZHEIMER'S DISEASE

According to the 1989 National Hospital Discharge Survey, an estimated 117,000 patients were discharged from short-stay hospitals in the United States with a diagnosis of Alzheimer's disease on the medical record. In almost all cases, this diagnosis was a secondary diagnosis; in less than 10,000 cases was Alzheimer's disease the principal diagnosis listed on the medical record.

The Supplement on Aging to the 1984 National Health Interview Survey included Alzheimer's disease on the condition list, and the data from this supplement are now available on public use data tapes. However, the small number of cases suggest that there is underreporting of this condition.

Numbers of deaths attributed on the death certificate to Alzheimer's disease have increased markedly in recent years according to data from the National Vital Statistics System. In 1979, a total of 857 deaths due to this cause were reported in mortality data from NCHS. By 1988, the number had increased to 12,281; over 14 times the number in 1979. Data for 1987 show that this condition was mentioned as contributing to, but not as the underlying cause (11,311), for an additional 14,639 deaths.

Health Care Financing Administration

INITIATIVES CONCERNING ALZHEIMER'S DISEASE
AND RELATED DEMENTIASNATURE/MAGNITUDE OF THE PROBLEM

A patient with Alzheimer's disease or a related dementia generally requires a full range of medical and personal care services during the course of his/her illness, including hospital, community and home health services, and institutional long term care. It is estimated that more than half (55 percent) of patients in long term care facilities have Alzheimer's disease or a related dementia. Nonetheless, it appears that a greater number of persons with dementia reside at home or in the community than in institutions. According to a study funded by the National Institute on Aging, the total costs, including the direct costs of providing services and indirect costs, were roughly estimated to be \$8 billion in 1983. A major goal of all services has been to keep the patient at home or in the community, if feasible.

An improved understanding of different approaches to better coordinating health, social, and personal care services for dementia patients and their families--with determination of associated costs--has been another services research challenge. The cost of providing needed health, social, and personal care services for these individuals and their families varies dramatically according to the severity and length of time of the patient's illness, among a number of other factors. Two problems in determining total costs for these individuals and their families are that (1) some of the major third party payers of care (i.e., Medicaid and private health insurers) do not routinely categorize their cost data according to patient diagnosis and (2) it is difficult to obtain data about how much is being spent by families and the community in providing needed services to the individuals and their families. At this time, no major studies have been conducted that can provide reliable and accurate information on total (or even average) costs for these individuals and their families.

Medicare

Medicare coverage is determined by the nature of the services required and not by the specific diagnosis of the patient. Therefore, dementia patients are covered for Medicare benefits no differently than other elderly patients requiring medical services. The following is a breakout of dollars reimbursed by Medicare to institutions providing care to patients with Alzheimer's disease or a related dementia in 1985: \$574 million to hospitals and \$11 million to SNFs. In addition,

Medicare paid approximately \$175 million to physicians and \$1.5 million to HHAs providing services to these patients.

Medicaid

Coverage under Medicaid is limited to low-income individuals and families. Only 8 percent of the elderly are covered under Medicaid. However, it is estimated that between 15 and 20 percent of individuals with dementia are covered under Medicaid. Once the individual with Alzheimer's disease or a related dementia becomes eligible for Medicaid, he or she is covered under the program for a much wider array of health, medical and personal care, and long term care services than the patient covered only under Medicare. In addition to covering the services such as hospital, SNF, ICF, and physician services, States are given the flexibility of covering under the Medicaid program home, community-based, and ambulatory services such as personal care, private duty nursing, physical therapy, clinic services, and medication costs.

Private Health Insurance Programs

Significant changes having been occurring in the private long term care insurance market. Nationwide the number of individual long term care policies has doubled in the last 2 years to an estimated 500,000, provided by over 70 companies. Early private long term care insurance products (1986) were limited by the fact that they tended to cover acute and subacute care services (i.e., SNF services) but to exclude in-home health care and personal care services. Also, these early plans always limited the amount and/or length of coverage. Many of the more recent private long term care policies provide coverage of custodial and personal care services, home care benefits, case management services, and consumer protection features such as guaranteed renewability and inflation protection. In spite of these advances, less than 2 percent of all elderly have any private long term care insurance protection and the industry is still considered in its infancy.

Areas of Need

The most significant problems with current Medicare, Medicaid, and private health coverage are summarized below:

- o While about 90 percent of all patients with Alzheimer's disease or a related dementia are eligible for Medicare, most of the services actually required for management of the disease (i.e., long term care and personal care services) are not covered in Medicare's benefit package.
- o While many, if not most, of the services required by

patients with dementia and their families are covered as a benefit under the Medicaid program, most individuals with Alzheimer's disease or a related dementia and their families must "spend down" their assets in order to become eligible for Medicaid coverage.

- o While strides have recently been made in private long term care insurance, there is still limited coverage of long term care services by private insurers for persons with Alzheimer's disease or a related dementia.
- o While we are able to get estimates of the costs to the Medicare program for providing various services specifically to patients with Alzheimer's disease and related dementias, it is much more difficult to obtain cost estimates from other third party payers (Medicaid and private health insurers) and from individuals and families affected by these illnesses.

HCFA PROGRAM AND RESEARCH INITIATIVES

Medicaid Home and Community-Based Waivers (2176 Waiver)

Since 1982, HCFA has been granting specific waivers to States permitting Medicaid coverage and reimbursement for home and community-based services provided to individuals who would otherwise need care in a nursing home or other institutional setting. Total expenditures in fiscal year 1989 under the program were \$993 million for a total of 144 specific waivers. Patients with Alzheimer's disease or related dementias and their families who are eligible for Medicaid, and who are in localities and States covered under the waivers, are provided special services such as adult day care, respite care, homemaker care, and case management services to delay or prevent institutionalization.

Medicare Alzheimer's Disease Demonstration Projects

HCFA is conducting the Medicare Alzheimer's Disease Demonstration in response to section 9342 of the Omnibus Budget Reconciliation Act of 1986. The purpose of the demonstration is to determine the effectiveness, cost, and impact on health status and functioning of providing comprehensive services for individuals entitled under Medicare who are victims of Alzheimer's disease or related disorders. Section 9342 specified that the demonstration projects are to be conducted over a 3-year period, include services designed to meet the specific needs of Alzheimer's disease patients, be conducted by organizations that either directly or by contract are able to provide comprehensive client evaluations and additional services, and be conducted in sites that are geographically diverse and readily accessible to Medicare beneficiaries.

Section 4164 of the Omnibus Budget Reconciliation Act of 1990 has extended the demonstration by an additional year.

In June 1988, 51 organizations and agencies from across the country, representing a wide range of public programs and health care providers, submitted applications to serve as sites in the demonstration. Eight applicants were selected as demonstration sites: Monroe County Long Term Care Program, Inc., Rochester, New York; Carle Clinic, Urbana, Illinois; Northeast Community Mental Health Center, Memphis, Tennessee; Good Samaritan Hospital and Medical Center, Portland, Oregon; Cincinnati Area Senior Services, Inc., Cincinnati, Ohio; Wood County Senior Citizens Association, Parkersburg, West Virginia; the Wilder Foundation, Minneapolis, Minnesota; and Miami Jewish Home and Hospital, Miami, Florida. These awards were made based on the results of the technical evaluation of the applications and in consideration of the need for geographic dispersion, a mix of urban and rural environments, and sites with a diversity of organizational characteristics.

Medicare beneficiaries who are entitled to Part A of Medicare and enrolled in Part B of Medicare, have a primary diagnosis of Alzheimer's disease or a related disorder, and reside within the demonstration site's catchment area, are eligible to participate in the demonstration. The services that may be provided by the project sites under the demonstration include: case management; home and community-based services such as adult day care and personal care services; and education, counseling, respite, and other supports for the primary informal caregiver (the family member who provides the most informal care) of the Alzheimer's patient. Although all project sites operate within uniform parameters established by HCFA, innovation in the delivery of specific services is encouraged.

The demonstration is testing two models that involve variations in the level of Medicare reimbursement and the intensity of case management.

- Model A provides Medicare reimbursement for a wide range of community services specified above within an overall monthly expenditure cap of \$300 for each client. This model will provide information on what services are needed by Alzheimer's clients and their caregivers, the costs and benefits, and how these vary for different types of clients and caregivers. These sites will operate with a case manager-to-client ratio of 1:100.
- Model B includes the same range of direct services as Model A, but with a higher overall monthly expenditure cap of \$500 per client. The difference in reimbursement levels between the two models will provide information about (1)

the effects of reimbursement on desired impacts, (2) which services are considered most essential to these families and how these vary across different types of clients and caregivers, and (3) whether families are willing to purchase additional services using out-of-pocket funds when the availability of these services has been improved. In addition, Model B sites will operate with a case manager-to-client ratio of 1:30 in order to observe the effects of different levels of case management intensity on site operations and family impacts.

Under both models, HCFA pays 80 percent of the costs of direct services, with clients responsible for a 20 percent copayment. (Clients who are Medicaid recipients are not responsible for copayments.) Both models permit a wide range of direct services to allow sites flexibility in working with local resources to meet individual needs. The difference in the service funding level across the two models will provide estimates of the differential impacts of alternative levels of caps in Medicare expenditures.

HCFA expects to serve a total of approximately 2,400 patients during the demonstration, with an equal number of patients randomly assigned to a control group.

After a 6-month planning phase, the enrollment of clients and provision of services to these clients began in December 1989. Enrollment of clients by the demonstration sites is scheduled to continue through April 1991, followed by 19 months of steady state operations and a 6-month phasedown period. The demonstration is scheduled to end in May 1993.

To finance this effort, the legislation authorizes expenditures from the Medicare trust funds of not more than \$55 million for the demonstration projects and \$3 million for the evaluation of the projects. The legislation also requires that two reports be prepared. The first is a preliminary report to be made to Congress during the fourth year of the projects. This report would include a description of the services offered and the sites at which the demonstration projects are being conducted. The second is a final report which will be submitted at the completion of the demonstration.

HCFA awarded a contract in September 1989 to the University of California, San Francisco for an independent evaluation of the demonstration. Some of the questions that the evaluation will address include: (1) What factors are associated with the cost-effectiveness and impact on health status of providing expanded services to Medicare beneficiaries with Alzheimer's disease or a related disorder and their caregivers?; (2) What are the effects of the provision of an expanded range of services, including caregiver support and counseling services,

on caregiver burden?; and (3) What are the effects of alternative reimbursement caps on service utilization and on the distribution of the burden of cost for public and private payors?

The evaluator also provides technical assistance to the sites in order to assure consistency of the data being collected for the evaluation.

New Jersey Respite Care Pilot Project

The Omnibus Budget Reconciliation Act of 1986 also directed the Secretary to establish a program to assist families in the care of elderly and disabled relatives. The New Jersey Respite Care Pilot Project was developed to determine the impact of providing respite care services, both on elderly, functionally impaired care-recipients who are considered at risk of institutionalization and on their caregivers. The project focuses on two key issues: whether respite services effectively reduce institutionalization, and whether they relieve caregivers' physical, emotional, and financial stress and enhance the role of the family in providing long term care services. Based on experience with other respite care projects supported by HCFA, it is estimated that a significant portion of the individuals enrolled in this project may have Alzheimer's disease or a related dementia.

In compliance with the legislation, the respite care services provided under this project include: short-term and intermittent companion services; homemaker, home health aide and personal care services; adult day care, both social and medical; and inpatient respite care in a hospital or nursing home. Services are available on a planned or emergency basis. Inpatient respite is limited to a total of 14 days a year for each client. In addition to these services, peer support, training, and counseling are provided to family caregivers.

All of New Jersey's 21 counties are participating in the project. The State administers and operates the program in each county by contracting with a local provider or government agency. These designated sponsoring agencies receive a yearly budget based on that county's proportion of the target population. Expenditures for each client were limited to a maximum of \$2,400 during the first year; this amount will be adjusted annually. Clients are charged a co-payment that is calculated on a sliding scale based on their income. Federal payments under this demonstration cannot exceed \$2 million per fiscal year. Federal funding for this project began on July 1, 1988. Section 4746 of the Omnibus Budget Reconciliation Act of 1990 extended this project through September 30, 1992.

Community Care for Alzheimer's Disease and Related Disorders

HCFA has sponsored a study by the Urban Institute in Washington, D.C. to analyze and compare data for persons cognitively impaired versus those cognitively intact who participated in the National Long Term Care Channeling Demonstration project which was conducted between 1980 and 1985. Of the project's 6,326 functionally impaired clients, almost half of this population had some degree of cognitive impairment, in most cases Alzheimer's disease. The two specific objectives of the current project are (1) to determine the range of services, sources, and costs of care used by community residents with cognitive impairment due to Alzheimer's disease and related disorders (ARD); and (2) to determine the risks of these residents entering nursing homes as a function of their physical and mental health status. Urban's report contains valuable information in an area where little quantification has been performed; that is, the types and costs of services ARD clients use and the factors associated with admission to nursing facilities.

In addition, in 1990 the Health Care Financing Administration has approved an additional study by the Urban Institute through the Brandeis University Policy Center to assess the feasibility of using a longitudinal data base from the Triage/Connecticut Community Care, Inc. program in Connecticut. This data base contains details on patient assessment and management systems that may provide additional information on the costs of persons with Alzheimer's and related diseases.

Adult Day Center Census

This study will provide information on service scope and availability, costs and financing, quality assurance mechanisms and users of services in adult day care centers. The study was conducted by a research team from the Institute for Health and Aging at the University of California, San Francisco, and the National Institute of Adult Daycare. Funding was provided by HCFA and the American Association of Retired Persons. Of over 2,000 operating centers who were identified, 1,425 centers completed the survey. When discussing users of services, the researchers indicate that participants usually suffer from multiple problems, with 40 percent requiring assistance in three or more activities of daily living. One-third of participants suffer from Alzheimer's or related disorders. The final report entitled, "The National Adult Day Census - 89, A Descriptive Report," will be available in early 1991.

Study of Out-of-Home Respite Care

This study was originally mandated by the now repealed Medicare Catastrophic Coverage Act (MCCA) to determine the cost and

appropriateness of expanding MCCA respite benefits to include out-of-home services. Brandeis University will report on what factors should be taken into account in considering a respite care program under public or private insurance. This report will include a review of the benefits currently being offered in the U.S., what services are being provided under existing programs, what services are likely to benefit which populations, and some estimates of costs of different respite service packages. The study uses information available from existing data sets and ongoing respite programs and demonstrations. The study report is expected to be available in early 1991.

Program of All-inclusive Care for the Elderly

HCFA is directed by section 9412 of Public Law 99-509 (the Omnibus Budget Reconciliation Act of 1986), as amended, to conduct a demonstration which replicates, in not more than 15 sites, the model of care developed by On Lok Senior Health Services in San Francisco, California.

The Program of All-Inclusive Care for the Elderly (PACE) demonstration has the purpose of replicating a unique model of managed care service delivery for 300 very frail community dwelling elderly most of whom are dually eligible for Medicare and Medicaid coverage and all of whom are assessed as being eligible for nursing home placement according to the standards established by participating states.

The model of care includes as core services the provision of adult day health care and multidisciplinary case management through which access and allocation of all health and long term care services are arranged. Physician, therapeutic, ancillary and social support services are provided on-site at the adult day care center whenever possible. Hospital, nursing home, home health, and other specialized services are provided extramurally. Transportation also is provided to all enrolled members who require it.

Financing of this model is accomplished through prospective capitation of both Medicare and Medicaid payments to the provider. Demonstration sites are to assume financial risk progressively over three years, as stipulated in P.L. 100-203.

The PACE sites include East Boston, Massachusetts; Bronx, New York; Portland, Oregon; Columbia, South Carolina; Milwaukee, Wisconsin; Denver, Colorado; Chicago, Illinois; and El Paso, Texas. East Boston, Portland, Columbia, and Milwaukee began PACE service delivery in 1990; the remaining sites are in various phases of development, and all sites are expected to be operational by December 1991.

A two stage evaluation of the PACE demonstration is to be conducted. The first stage involves an 18-month case study which began in September 1989, of the On Lok/PACE model as practiced at the original site and as implemented at the PACE sites. This study was awarded to the University of Minnesota. The second phase will examine PACE sites before and after full financial risk. An evaluation contract will be awarded in 1991 for this outcome evaluation. Though not dealing exclusively with persons with Alzheimer's disease per se, a large proportion of PACE enrollees are cognitively impaired. Therefore, some findings relevant to patients with dementia should emerge.

Social/Health Maintenance Organization Demonstration

The Social/Health Maintenance Organization (S/HMO) is a novel concept for financing and expanding long term care coverage benefits for Medicare patients. Through the S/HMO, Medicare pays a fixed monthly capitation amount (as in an HMO), so that beneficiaries are eligible to receive a package of long term care benefits, as well as medical and acute care. Long term care services are available, however, only up to specific limits for beneficiaries meeting site-specific eligibility criteria. Reflecting the general population, approximately 5 percent of enrollees are severely impaired persons who are certified for nursing home placement based on Medicaid criteria. Four S/HMO demonstration projects were initiated in January 1985 and will operate through 1995. An evaluation of these four sites is being performed by the University of California, San Francisco and the findings are expected to be available in the summer of 1991. Four additional sites have been authorized by the Omnibus Budget Reconciliation Act of 1990 and are expected to be operational by 1992. These sites will also operate through 1995. Though not dealing exclusively with persons with dementia per se, some findings relevant to patients and families with Alzheimer's disease should emerge.

NATIONAL INSTITUTES OF HEALTH

National Institute on Aging

ALZHEIMER'S DISEASE

Perhaps no other disease rivals Alzheimer's disease (AD) in its impact on the family and cost to society. It has been called the quintessential long-term care issue because of the disease's enduring nature and the breadth of health and social services required to deal with it. Victims can live for 20 years or more as this illness gradually erodes the mind and, eventually, the capacity for life itself, while bankrupting the families who provide their care.

Four million older Americans currently suffer from AD. The fact that the incidence of this disease increases dramatically with age, taken together with the reality of an aging population, makes conquering this dread disease a national imperative.

The battle is being fought on a number of research fronts. At NIH, the "troops" include the National Institute on Aging (NIA), the National Cancer Institute (NCI), the National Institute of Dental Research (NIDR), the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Allergy and Infectious Diseases (NIAID), the National Institute of Child Health and Human Development (NICHD), the National Institute of Environmental Health Sciences (NIEHS) the National Center for Research Resources (NCRR), and the National Center for Nursing Research (NCNR). Also, the National Center for Human Genome Research supports research on the development of maps--which show the location of certain identifiable landmarks --of human chromosomes. These should aid scientists in their search for genetic causes of AD and other diseases.

Alzheimer Centers Provide Unique Opportunities; Speed Progress of Research

Many of the research advances reported this year are made possible through the concerted efforts of NIA's 15 Alzheimer's Disease Research Centers (ADRCs). These Centers, located in major medical institutions around the country, support a multi-disciplinary research program in AD. Each ADRC has administrative, clinical, neuropathology, and education and information transfer cores. The Centers network is critical to carrying out large-scale, high quality clinical trials to deliver effective treatments to Alzheimer's disease patients and their physicians.

Many of the ADRCs build upon existing resources within their institutions which are funded by the NCRR, whose research contributions are described later in this report.

Scientists Unravel Clues to Alzheimer Plaques and Tangles

The hallmark pathological features of AD seen at autopsy, amyloid plaques and neurofibrillary tangles (tangled nerve cell fibers) within the brain, have a complex and intriguing biochemistry. A number of clues have emerged, for example, concerning the beta-amyloid plaques. The beta-amyloid protein is part of a larger molecule called the amyloid precursor protein (APP), one form of which resides in the cell membrane. In the last year, a great deal has been learned about the structure and function of the normal APP molecule in various cells of the body, and how it may be abnormally processed in AD.

Scientists at Athena Neurosciences in San Francisco, California, and Eli Lilly and Company in Indianapolis, Indiana, as well as Dr. Donald Price and colleagues at The Johns Hopkins University ADRC, in Baltimore, Maryland, have shown that beta-amyloid is the product of abnormal cutting of the APP molecule.

Candidates for proteins involved in the abnormal cutting of APP include proteases (enzymes) normally found in the cell's lysosomes, structures involved with cellular digestion. Dr. Ralph Nixon and colleagues at Harvard University in Boston have found active lysosomal proteases surrounding amyloid plaques in AD brain.

In addition, Dr. Dennis Cunningham and colleagues at the University of California at Irvine have identified a potential role in AD for protease nexin 1 (PN-1), which inhibits thrombin, a substance needed for blood clotting. Levels of unbound, or available, PN-1 are substantially reduced in AD brain, apparently in favor of a form that is bound with some other substance. The reduction in PN-1 implies a reduced ability to inhibit thrombin activity in the brain. Thrombin has been shown by Dr. Gregory Cole and colleagues at the University of California ADRC in San Diego to stimulate the release of a beta-amyloid-containing form of the amyloid precursor from platelets. Neurons apparently contain thrombin receptors as well.

This research has strengthened interest in the idea that brain amyloid may have its origin in the circulation. This was suggested by an earlier observation of Dr. Dennis J. Selkoe and colleagues at the Harvard ADRC that material similar to amyloid was found in the skin of Alzheimer's disease patients.

Abnormalities in the cytoskeleton, the nerve cell's dynamic internal framework, are a prominent feature in the Alzheimer brain, and under active investigation in numerous laboratories. Disturbances in the cytoskeleton's function could affect energy metabolism, the structure of nerve cell endings, and the ability of these cells to form new connections. Such disturbances could also impede the flow of necessary materials, including messages and nutrients to the nerve endings. Scientists think that a damaged cytoskeleton represents a stage in the death of nerve

cell endings, or processes, and may correlate closely with the patient's degree of dementia.

The hallmark cytoskeletal defect in AD is the presence of neurofibrillary tangles (NFTs) within nerve cell processes. According to date recently obtained by Drs. Virginia Lee and John Trojanowski and colleagues at the University of Pennsylvania, NFTs apparently consist largely of abnormal forms of a cytoskeletal protein known as "tau" and originally identified by NIA grantee Dr. Peter Davies and colleagues at New York University. The abnormal "tau" takes the form of paired helical filaments (PHF) or twisted fibers at least in part through protein phosphorylation, a process whereby phosphorus is added to proteins. Proof of the mechanism of PHF generation awaits test-tube conversion of normal human tau to PHF.

A major unanswered question in AD is the cause of the decline and eventual death of neurons. Do amyloid plaques and NFTs represent causes or only symptoms of some undetected neuronal disease process? Recently, the beta-amyloid protein was shown by Dr. Bruce Yankner and colleagues at Harvard University to have both growth-promoting and toxic effects on neurons in cell culture, depending on the developmental stage of the cells and the concentration of the protein. In cultures of normal cells from the brain's hippocampus (a structure severely affected in AD), beta amyloid was a thousand times more toxic than glutamate, a chemical long suspected to be involved in neurodegenerative diseases. These observations suggest that beta amyloid could normally function as a trophic or growth-promoting factor during cell development early in life, but that accumulations of amyloid in mature brain may lead to nerve cell degeneration.

The Quest for a Genetic Link

In the search for genes and gene products that may play a role in the cell deterioration of AD, scientists continue to pursue cases where the disease runs in families. While most cases of AD occur sporadically and are probably not inherited, the discovery of a gene for a familial form of Alzheimer's disease (FAD) would shed light on other potential causes.

Intensive efforts are under way to confirm potential linkages between early-onset FAD (disease occurring prior to age 65) and genes on chromosome 21. Such a linkage was reported earlier by researchers at the Harvard/Massachusetts General Hospital ADRC. Additionally, a linkage was tentatively identified earlier this year between a gene on chromosome 19 and late-onset FAD (disease appearing after age 65) by Dr. Allen Roses and investigators at the Duke University ADRC in Durham, North Carolina. (Further information on a genetic link is described in the NINDS section of this report.) The Duke investigators are sharing blood samples from FAD patients

and their families with scientists at the Harvard and University of Washington ADRCs in an attempt to confirm each other's findings. A large early-onset family studied by researchers at the University of Washington ADRC has been shown not to be linked to chromosome 21. These studies imply that AD is not a single disorder, but a group of similar disorders with different causes.

The probable genetic mechanism for another inherited disease in which beta-amyloid accumulates in the brain has been identified by Dr. Blas Frangione and colleagues at New York University in New York City. These researchers have shown that the cause of this inherited amyloid disease hereditary cerebral hemorrhage with amyloidosis of Dutch type, in which amyloid is deposited in brain blood vessel walls and leads to fatal strokes, is probably a mutation of a single base (one of the four types of molecules that make up DNA) within the amyloid sequence on chromosome 21. This mutation apparently reduces the effectiveness of normal proteolytic processing, suggesting a potential mechanism for amyloid formation. Other factors besides the amyloid gene sequence itself are involved in amyloid processing. Research is focusing on the identification of these other factors that might contribute towards non-vascular brain amyloid, including proteases and phosphorylation enzymes.

This year a National Cell Bank was established to collect information on family histories and blood samples from families affected by AD. The need for such an extensive effort is based on the fact that information on family pedigrees is notoriously difficult for individual researchers to obtain, and the reliability of research findings depends on amassing large numbers of suspect families. The Cell Bank utilizes the talents of Dr. Michael P. Conneally at Indiana University in Indianapolis, who has successfully established national cell banks for other major disorders including Huntington's disease, and the technical expertise and resources of staff at the Duke ADRC. The Cell Bank will serve as an important resource, not only to facilitate ongoing genetic research, but to attract new talent to attack the problems of AD.

THA Study Being Evaluated

The two-year clinical trial to test the safety and effectiveness of the drug tetrahydroaminoacridine or THA was cut short in order to speed up analysis and dissemination of results. THA blocks the otherwise rapid breakdown of the neurotransmitter acetylcholine in the Alzheimer brain. Principal investigators, Drs. Kenneth Davis at Mount Sinai Medical Center in New York City and Leon Thal at the University of Southern California in Los Angeles, determined that a sufficient number of patients were enrolled in the study to evaluate the drug. While the investigators caution that their action by no means indicates the drug is either effective or ineffective, the Institute is hopeful that some benefit will be derived from it and that this study will pave the way for further testing of the many compounds

that show potential for the treatment of AD.

National Registry on Alzheimer's Disease Established

In the absence of a clearcut cause or any marker to distinguish persons with AD, efforts continue to improve diagnostic techniques. The NIA Consortium To Establish a Registry for Alzheimer's Disease (CERAD) is a group of physicians and scientists at 22 university medical centers who are attempting to develop uniform methods to evaluate Alzheimer patients. Now in its fifth year of operation, CERAD has enrolled over 700 Alzheimer patients and 500 healthy control subjects. Participants will be followed from their entry into the study until death to learn how brain tissue and mental function change with normal age and throughout the course of AD.

CERAD presents the opportunity for special studies, which include collecting information about AD in minorities and developing foreign language versions of CERAD test instruments. Information is being collected on Black and Hispanic Americans. With the assistance of foreign collaborators, CERAD instruments have been translated into Dutch and French while Spanish versions were produced by CERAD participants at the University of Southern California. The ability of these instruments to assess the health of persons of different ethnic origins and with varying educational levels is being explored. Instructional videotapes for clinicians are also being developed in different languages.

Preliminary Findings from CERAD Study Reported

With 5 years' experience to draw from, CERAD is beginning to yield some preliminary findings. One recent report finds that the test of delayed recall--a word list recalled by the patient after a period of time has elapsed--is the best measure for distinguishing early AD cases (mild dementia) from healthy individuals. This finding was reported by Dr. Kathleen Welsh and her colleagues at the Duke ADRC.

Dr. Chris Clark and colleagues, also at Duke, report that neuropsychological test performance correlates with brain atrophy shown with MRI (magnetic resonance imaging), a type of scanner that can produce images of the brain.

Comparing three widely used mental status tests, Drs. David Salmon at the Veterans Administration Medical Center in San Diego and colleagues at the University of Southern California find that the Mini-Mental State Exam (MMSE), the Dementia Rating Scale (DRS), and the Information-Memory-Concentration test (IMC), often called the Blessed Memory scale, are equally effective for evaluating early to middle stage AD. However, only the DRS was sensitive enough to follow the progression of severely demented patients. Measured by any of the three tests, the average rate of decline in year one bore no relationship to the rate at which the disease progressed by the third year, and thus may not be useful in predicting how rapidly the disease will progress.

PET Scans May Be Used to Predict Type of Deficits in AD Patients

NIA Intramural scientists directed by Dr. Stanley Rapoport are gaining new insight into the diversity of AD through the use of positron emission tomography (PET), a brain scanning technique that measures brain metabolism and cerebral blood flow.

NIA's Dr. Cheryl Grady and colleagues have found that metabolic changes, as measured by PET, precede the appearance of neuropsychological deficits (impairment of thought processes) in Alzheimer patients by anywhere from a few months to a few years. The researchers were able to categorize patients into four subgroups based on PET scan readings. About half of all Alzheimer patients had deficits located primarily in the part of the brain called the parietal lobe; others have deficits in the paralimbic cortical region, in the left hemisphere of the brain, or in the brain's frontal lobes. The NIA researchers have found they can use the pattern of metabolic deficits to predict the types of functional problems that eventually emerge. Early-stage AD patients who had specific metabolic deficits in the left side of the brain, which controls language processes, went on to develop communication difficulties. Patients who had damage predominantly on the right side of the brain later developed specific problems in processing visuospatial information (placement of objects in the environment). Such patients may have difficulty negotiating their environment, remembering how to find their way in familiar surroundings, or pairing a name with a face, for example.

The patterns of metabolic and neuropsychological deficits (impaired thought processes) appear to persist well into the later stages of AD. The ability to foresee the probable course of AD in individuals should help patients and their families with care planning, and should help in gauging the effectiveness of various treatments, since deviations from the expected progression of the disease that result from the administration of particular treatments can be more accurately measured.

Down Syndrome May Serve as a Model for Alzheimer's Disease

NIA scientist Dr. Mark Schapiro has found that similarities between older patients with Down syndrome and AD may offer insights into common mechanisms and treatments for these diseases.

Down syndrome is a genetic disorder evident at birth that results from the inheritance of an extra portion of chromosome 21. As they reach age 35, Down syndrome patients invariably begin to develop the same brain plaques and tangles seen in Alzheimer patients, and at least one-third of them go on to develop dementia. This link between Down syndrome and Alzheimer-like brain pathology led to the identification of chromosome 21 as the location of the gene responsible for the production of amyloid. PET scans show that, like Alzheimer patients, demented

patients with Down syndrome show decreased brain metabolism in areas concerned with thought processes.

Besides accelerating the progress of drug studies, viewing Down syndrome as a model for AD may also help researchers in determining the relative importance of environmental versus genetic factors in the development of the disease. So far, PET Scans and analyses of autopsied tissue, have uncovered no differences between patients with familial AD and patients with the sporadic form of the disease.

Field Office to Study Dementia in Japanese Established

Through its Epidemiology, Demography, and Biometry Program (EDB), NIA has established an Asia-Pacific Office in Honolulu, Hawaii, to study dementia and aging. This office, headed by Dr. Lon White, former chief of EDB's epidemiology office, will oversee a project called the Honolulu Asia Aging Study (HAAS), which is being conducted in cooperation with the National Heart, Lung, and Blood Institute. Approximately 5,000 men of Japanese ancestry have agreed to participate in the study, which will provide a rare opportunity to determine the rates and risk factors for AD and multi-infarct dementia (caused by many small strokes) in this population. (Japan is the only industrialized country that consistently reports higher rates of vascular or stroke-related dementia than AD.) Wives of a subgroup of the participants will be examined as part of a special followup. The HAAS is being coordinated with parallel studies being developed at sites in Japan (Hiroshima, Tokyo, and Osaka), Taiwan, and Seattle.

Researchers Profile Caregivers' Needs and Strategies

A great deal has been learned over the past decade about the families who care for Alzheimer patients. We now know that spouses provide most of the care, that most caregivers are women, and that families often provide care for many years, in spite of tremendous financial and personal cost. Investigators are now asking why do some caregivers cope more effectively than others, what makes some caregivers persist in their caregiving role while others drop out, and how we can assist those who want to provide care to continue doing so.

A study at the Western Psychiatric Institute and Clinic in Pittsburgh finds considerable difference in the way people cope with and react to the ongoing stress of caring for Alzheimer patients. Drs. Richard Schulz and Gail Williamson report that over a 2-year period, female caregivers were consistently more depressed than male caregivers. Those most severely affected were women who had financial concerns, cared for patients that frequently exhibit problem behaviors, and received little assistance from others.

Two factors may protect against depression in caregivers. Men and women who have what the investigators call a communal orientation--those who believe strongly that people should help each

other--fared better in terms of avoiding depression. This finding was true for all caregivers, regardless of the amount of care they actually provided. Those who report having had a close relationship with the patient prior to his/her illness also felt less burdened.

The two situations cited as being most difficult were coping with the memory loss itself, and the general decline of the loved one. Strategies helpful in confronting the patient's memory loss include doing something relaxing caregiver and accepting the reality of the patient's deficit. Seeking social support helps caregivers cope with the patient's decline. Those caregivers who wish the problem would go away, keep their feelings to themselves, or try to see the situation in a different light are more prone to depression. The investigators caution that while women tend to use less effective coping strategies, it was unclear whether these strategies resulted in depression or were a response to it.

Research Suggests Ways To Expand Community-Based Long-Term Care Services to Alzheimer Families

Studies conducted by Dr. Charles Given and associates at Michigan State University in East Lansing provide direction for refining policies regarding long-term home care. More than 500 persons who have provided care for several years to physically and/or cognitively impaired patients were asked which activities of daily living required the most assistance. Dr. Given found that some tasks require much more assistance than others. For instance, helping someone with mobility problems move from a bed to chair is much more demanding than helping the patient eat or get dressed, and is more likely to require assistance beyond that which the primary caregiver alone can provide. Because simple counts of numbers of dependencies in activities of daily living do not take these differences into account, the provision of assistance to families should be based on the type, rather than number, of dependencies.

The Michigan investigators also found that AD families use fewer community services than those caring for patients with other conditions. Reasons cited include affordability, lack of knowledge about services or how to gain access to them, and insensitivity of service providers to the patients' needs. The researchers recommend that health providers and other professionals assume more responsibility for linking families with community-based care and for explaining when and how to use such services. The investigators also suggest that agencies design their programs and train employees to respond to the multidimensional needs of these patients and their families.

Educational Activities Benefit Professional and Family Caregivers

The ADRCs are actively involved in professional training and outreach. In addition to fostering clinical and research skills, the Centers work with local Alzheimer's Association chapters to conduct educational activities for the general public.

An important function of each ADRC's Education and Information

National Institute of Neurological Disorders and Stroke

The National Institute of Neurological Disorders and Stroke (NINDS), as the principal source of support for neurological research in the United States, is a major participant in the study of AD. NINDS-supported scientists are pursuing a wide variety of research leads to expand knowledge of this complex disease. Basic studies seek to determine its underlying causes and effects while clinical research sharpens physicians' skills at diagnosing and treating patients.

Defining Who Is at Risk

Drs. Miriam K. Aronson and William H. Frishman

at the Albert Einstein College of Medicine of Yeshiva University in the Bronx, New York, have recently linked AD in older women with heart attacks. The investigators studied healthy men and women aged 75 to 85 to explore risk factors associated with dementia. The participants were evaluated to determine changes in their health and mental status. The scientists found that those women who had a heart attack were 5 times more likely to develop AD than other women in the study; heart attacks among male participants did not appear to be similarly associated with an increased risk of the disease. Other factors studied by the scientists--age, head injury, thyroid disease, educational level, and family history of dementia--did not appear to increase risk. Further study will show whether the prevalence of AD can be decreased if women lower their risk for heart attacks by changing their diets, smoking habits, and other cardiac risk behaviors.

NINDS intramural scientists Drs. Vijay Chandra and the late Bruce S. Schoenberg, and their colleagues studied the relationship between head trauma with loss of consciousness and the development of AD. Their results, published this year, found no significant link between the two.

More Specific Diagnostic Tests and Better Treatments Sought

As yet, there is no specific diagnostic test for AD. NINDS grantee Dr. Kenneth M. A. Welch at Henry Ford Hospital in Detroit, Michigan, and his colleagues recently used MRI scans to measure compounds involved in the brain's use of energy in 10 patients with a form of multi-infarct dementia (MID) in the subcortical area of the brain, 17 AD patients, and 17 healthy individuals. MID is the second most common cause of cognitive impairment in older people. Since it may be possible to prevent further decline in MID patients by altering their risk factors for stroke, it is important that physicians distinguish between the two disorders. By injecting patients with a phosphorus solution prior to doing the scan, the scientists were able to distinguish disease-related differences that enabled them to accurately classify 100 percent of subcortical MID patients and 92 percent of AD patients.

Transfer Core is to translate research-based knowledge into practical information and training tools for physicians and other health care personnel. One notable example is the University of California at San Diego whose Education Core activities are directed by Dr. Phyllis Lessen. Using a train-the-trainer concept, this Core has established a mini-residency that trains approximately 40 practicing health professionals each year. Many of the trainees are themselves educators who then further disseminate the newly-acquired information. Local medical faculty rotate through the mini-residency program, including faculty from all three health professional programs at San Diego State University. Four multidisciplinary geriatric care programs have been initiated in nearby clinical settings as a result of the mini-residency training.

To ensure adequate manpower in the field of AD, the Core is providing research and clinical training experiences to faculty of UCSD, clinical fellows, internal medicine students, neurology residents and medical students. The Core has been instrumental in introducing a new course in clinical geriatrics with a focus on dementing disorders into the UCSD medical school curriculum, enhancing future physicians' knowledge of the special considerations surrounding the diagnosis and care of dementia patients.

To reach health professionals in the community, the UCSD Education Core convenes several large meetings each year addressing the practical issues of caring for demented patients. The Core has also developed an audiovisual training tape on managing behavioral symptoms and a workbook for allied health professionals in nursing homes, as well as teaching materials to help nurses assess medication effects in AD (which should help reduce the problem of delirium in nursing home residents). The Core has also developed a brochure on safety in the home and automobile for use by family and professional caregivers.

Development of training materials for caregivers at the University of Washington ADRC in St. Louis, Missouri, and the ADRC at The Johns Hopkins University, are discussed in the NCNR section of this report.

The cost of caring for individuals with Alzheimer's disease and related dementias has been conservatively estimated to be \$38 billion to \$42 billion per year, for direct costs alone. The need for appropriate services and high-quality care will grow, especially since effective methods of prevention and cure are unknown at the present time.

Accomplishments

A Protein Found Only In Alzheimer's Disease Patients May Allow For Accurate Diagnostic Testing

At Albert Einstein College of Medicine, Dr. Peter Davies has discovered an abnormal protein, called A-68, in the brains of patients with Alzheimer's disease. This discovery may ultimately lead to a clinically useful diagnostic test for this disorder. Using a monoclonal antibody the researcher found that the antibody identifies the abnormal Alzheimer's disease associated protein in 85 percent of patients. The A-68 protein is not correlated with severity of clinical dementia, neuritic plaques, or old age per se. Research is continuing to determine whether the protein can be reliably assessed in the blood or cerebrospinal fluid of living patients.

Possibility Of Medication To Relieve Cell Loss

Charles B. Nemeroff and colleagues at Duke University are investigating the dynamic state of brain cholinergic neurons by measuring markers of neuronal integrity, neuronal activity, receptor number and function. Results, thus far, provide evidence of complete loss of ability by specific brain neurons to take up the precursor of acetylcholine, and an increased uptake of this precursor by the remaining cholinergic neurons in some brain areas. These results support the view that Alzheimer's disease involves neuronal metabolic dysfunction, as well as actual loss of neurons, and that in some brain regions the remaining neurons attempt to compensate by increasing transmitter production. These findings are significant since they point to the possibility of pharmacological manipulation to lessen the impact of cholinergic cell loss.

Two-Drug Combination Therapy

NIMH intramural scientists are developing new strategies to delay progression of symptoms of Alzheimer's disease. Previous work showed that the monoamine oxidase inhibitor, L-deprenyl, which delays symptoms of Parkinson's disease, was helpful in the symptomatic treatment of Alzheimer's disease. Long term investigations are underway to evaluate the possible neuro-protective effects of L-deprenyl. In an effort to expand the horizon of dementia therapies, the approach of combining different pharmacologic agents (e.g. physostigmine with L-deprenyl) is now increasingly being used in studies. Such combination approaches may prove to be the dominant therapeutic strategy in Alzheimer's disease for the 1990s.

Specific Cognitive Deficits Matched To Progressive Brain Disorders

The affects of Alzheimer's disease on speech and memory has led Dr. Kathryn Bayles at the University of Arizona to develop a series of sensitive communication disorder tests that demonstrate that even mildly affected Alzheimer's patients perform significantly more poorly than controls. Dr. Bayles has also devised a series of evaluations for late-stage Alzheimer's patients. Previously, the severe cognitive impairment of such individuals led them to be considered untestable. Dr. Bayles has found considerable variation in communication function. Mechanics of word reading and writing from dictation are easier and less affected than naming. These results yield the first indication of the relative difficulty experienced by Alzheimer's patients in performing common tasks.

Current Activities

Genetics

Today, genetic inheritance is the only etiologic factor identified for Alzheimer's disease, and thus the only confirmed clue to uncovering the mystery of the disease.

In earlier NIMH-supported research, Dr. Leonard Heston at the University of Minnesota discovered a remarkable etiologic clue to Alzheimer's disease in the form of an association with Down's syndrome. Individuals with Down's syndrome achieving 40 years of age develop symptoms similar to Alzheimer's disease. These similarities extend to enzymatic changes and the anatomical distribution of brain lesions. A second link between the two conditions has also been confirmed, wherein a significant excess of Down's syndrome births were found in families identified by a case of Alzheimer's disease. Other investigators subsequently located, on chromosome 21, the chromosome locus of Down's syndrome and genetic markers both for familial Alzheimer's disease and for the precursor of the abnormal amyloid protein found in brain plaques. Despite initial hopes that the two genes might be more closely linked, the most recent molecular studies have shown that the marker gene for familial Alzheimer's disease and the gene for amyloid protein reside at separate points on chromosome 21.

A linkage analysis study is now underway as a result of finding increased membrane fluidity in blood platelets in Alzheimer's patients. This abnormality is hypothesized to be a product of the Alzheimer's disease gene. There is now evidence that this membrane abnormality identifies a subgroup of patients with distinct clinical features--including an earlier symptomatic onset, a more rapidly progressive decline, and greater likelihood of a family history of dementia--and that it appears to be a stable, familial trait vertically transmitted in families through inheritance of a highly penetrant autosomal gene. Following the discovery that the genetic locus for this trait may reside on the long-arm of chromosome 21, linkage analysis is being used to

determine definitively whether the trait is located in this region or closer to a region associated with Down's syndrome, and whether it is distinct from the genes for familial Alzheimer's disease and the amyloid precursor protein. Further investigations are needed to determine the sensitivity and specificity of platelet membrane fluidity relative to Alzheimer's disease before its practical usefulness as a diagnostic marker for Alzheimer's disease can be determined.

As part of a larger initiative on the genetics of mental illness (The Diagnostic Centers for Psychiatric Linkage Studies), NIMH funded three sites (Harvard University, Johns Hopkins University, and the University of Alabama at Birmingham) to focus efforts on genetic research in Alzheimer's disease. The primary goal of the initiative is to establish a national resource of immortalized cell lines and clinical data from reliably diagnosed index cases and key relatives. Participants in this program are collaborating in developing a common protocol detailing diagnostic tools for both patients and relatives, determining appropriate small-family configurations and pedigree extensions rules for future linkage studies, and evaluating reliability of assessments. It is anticipated that one or more subsequent Request for Applications will be issued to support genetic analyses of the cells, and appropriate statistical analyses will be conducted to detect linkages as well as to test for hypothesized genetic heterogeneity.

This work will add to the ongoing investigation at the University of Minnesota that is establishing lymphoblastic cell lines on families affected by autopsy-proven diagnoses of Alzheimer's disease. Such tissue samples will be a permanent source of DNA, allowing characterization of the DNA sequences critical in Alzheimer's disease. NIMH has also been working with the National Institute on Aging to coordinate the efforts of their respective Alzheimer's gene bank initiatives, and will continue to encourage collaboration between their investigators to ensure the comparability of results despite differences in study designs.

Neuroscience Of Alzheimer's Disease

Both the mechanisms of brain aging and the neuropathology of age-related brain diseases are of enormous importance to the ability to differentiate normal aging from Alzheimer's disease and other dementias. In a new project, investigators in the NIMH Intramural Laboratory of Clinical Science are working to develop a human cell culture model suitable for studying Alzheimer's disease and other neuropsychiatric disorders. Cultures of proliferating human olfactory neurons (responsible for the sense of smell) have been established. The anatomic and functional characteristics of these cells are under investigation.

Dr. Carol Miller at the University of Southern California has identified different localized networks of neurons which are distinctively affected in Alzheimer's disease. Her results

reveal an unfolding, systematic course of changes from one to sixteen years after diagnosis. She has also discovered selective optic nerve degeneration and retinal abnormalities that suggest that the neurofibrillary tangles frequently found in the brains of Alzheimer's patients may not be required for cell death. Dr. Miller's studies are now comparing the neuronal changes found in Alzheimer's disease with those in other dementing diseases, such as Pick's and Parkinson's to help distinguish any changes that are specific to Alzheimer's disease.

Understanding basic mechanisms of memory function is critical for understanding the mechanics of Alzheimer's disease. The hippocampus, an important brain structure for memory storage, is severely affected in Alzheimer's disease. Research by Dr. Carl Cotman at the University of California, Irvine, suggests that it is possible to re-grow neuronal connections that have been severed in the hippocampus. Work is continuing on this promising finding which may make it possible to restore memory loss.

Neurochemical Regulation Of Memory

Dr. Michela Gallagher at the University of North Carolina is studying the neurochemical regulation of memory through an investigation of the status of cholinergic and peptidergic function and a range of behavioral parameters in the aged rat. Early detection of age-related impairments can be accomplished using tests of spatial learning, sensorimotor function, and circadian pattern of water intake. Biochemical studies show impairment in spatial learning to be proportional to increases in dynorphin (a peptide) levels in the hippocampus of aged rats. This work may have implications for mild cognitive impairments in normal human aging and emergence of dementia in Alzheimer's disease.

Neurotransmitter Studies May Lead To Medications

Several grantees are studying chemical neurotransmission abnormalities in the brains of Alzheimer's patients. Since loss of neurons that communicate via acetylcholine and acetylcholine depletion are almost always observed in the brains of those who have died from Alzheimer's disease, studies of this neurotransmitter have direct implications for understanding the disease. Dr. Paul Newhouse of the University of Vermont is employing a series of pharmacological probes to investigate how loss of brain cells and receptors correlates with cognitive deficits. By exploring the effects of a nicotine antagonist, mecamylamine, Dr. Newhouse hopes to determine whether the cognitive and behavioral deficits of Alzheimer's disease can be prevented.

A naturally occurring chemical, cholinesterase, is suspected to cause depletion of acetylcholine. Investigators at Southern Illinois University are now conducting a clinical trial of metrifonate, a chemical which was found to inhibit the production of cholinesterase as much as 80 percent, in a previous study with Alzheimer's patients. Cognitive performance in these patients

was improved according to various assessments, including reports by family members.

Many NIMH studies are increasing our knowledge of the mechanisms of neuronal communication and the multiplicity of chemical messengers available to nerve cells. Evidence has shown that a multi-faceted approach to the study of these chemical messengers is necessary for the development of medications to treat Alzheimer's disease.

Diagnostic Efforts In Alzheimer's Disease And Depression

Scientists in the Intramural Program are focussing on the frequent overlap of symptoms in depressed and demented patients. A diversity of methods is being used to test both Alzheimer's disease and depressed patients. Some of these measures, which include cerebrospinal fluid markers, urine metabolites, neuroendocrine responses, brain imaging techniques, neuropsychological cognitive testing, mood rating, and daily-activities assessment, are capable of distinguishing demented from depressed patients. However some of these measures show remarkable similarities among diagnostic groups, suggesting biological as well as clinical overlap between depression and dementia.

Another Intramural research group headed by Dr. Trey Sunderland has developed, and are continuing to test, a Dementia Mood Assessment Scale, designed specifically to rate mood in language-forgetful and sometimes entirely nonverbal Alzheimer's patients. This scale is helpful in tracking the variable mood states of dementia patients over the course of their illness, and may provide clues as to when antidepressant treatment may be indicated for these patients.

Dr. Patricia Prinz at the University of Washington is using EEG activity as a marker to discriminate mild dementia from normal aging and from elderly depression. She has been able to correctly classify 85 percent of normal aged from mildly demented subjects. Because the accuracy of formulating a differential diagnosis in the earliest stages of the disease has heretofore been so poor, and has been a major obstacle to treatment and longitudinal studies of the course of the illness, Dr. Prinz's finding represents a significant development.

Another non-invasive approach to diagnosis is using EEG sleep patterns, in particular rapid eye movements (REM). Dr. Charles Reynolds at the Western Psychiatric Institute and Clinic in Pittsburgh has found differences in REM activity among diagnostic groups. Both depressed and demented patients are distinguishable on the basis of his REM test from healthy controls. Longitudinal studies are ongoing in groups who are being followed to clarify relationships between persistent sleep abnormalities, pathogenesis, and illness course.

Assessment Of Cognitive And Motor Deterioration

The NIMH intramural Laboratory of Clinical Science is developing non-invasive procedures to identify patterns of cognitive deficit, to provide tools for accurately assessing cognitive change after pharmacologic intervention, and, most importantly, to test and develop models of normal cognitive functioning based on how such functions and systems break down following brain damage and disease. Results of recent studies of semantic memory, object recognition, spatial memory and visual attention by Dr. Martin and colleagues have suggested that Alzheimer's patients suffer from a disorganization or an actual loss of the specific types of knowledge that normally allow people to name objects. Ongoing studies are attempting to determine the extent to which these problems represent actual loss of knowledge and skill versus impaired access to relatively intact stores of information. Specified variations in the patterns of cognitive deficit in different Alzheimer's patients have been identified and may be helpful. Also under investigation is the question of whether normal learning of different types of information can be demonstrated in these patients using procedures that do not require conscious awareness of the learning event, and the relation between this type of learning and clinically-relevant cognitive deficits. Additional studies focus on patterns of attention and memory dysfunction in Alzheimer's patients and elderly depressed individuals.

Using multiple brain imaging techniques, Drs. Alan Kluger and Mony DeLeon of New York University are investigating the connections among cognitive impairment, motor dysfunction and white matter brain lesions. Their previous research found a decreased density of white matter in the brains of Alzheimer's patients. The Alzheimer's patients also have consistent and significant decreases in brain metabolism. Their current longitudinal research is testing the hypothesis that both Alzheimer's patients and normal elderly with white matter changes are at greater risk for cognitive/motor deterioration over time. Although these changes may be independent of Alzheimer's disease, they may add significantly to the brain-damage burden of the patient.

Another challenge to accurate assessment of cognitive function is the literacy level presumed by the testing instruments. Dr. Ramon Valle of San Diego State university has translated into Spanish and is validating for use with older Hispanics, two commonly used cognitive screening instruments: the Mini Mental Status Exam and the Blessed-Roth Dementia Scale. Dr. Valle has found that the Hispanic versions of these screening measures are valid with literate Hispanics but inadequate for the assessment of dementia in poorly educated individuals. This project addresses the need for culturally and educationally fair cognitive assessment devices for at least one segment of the growing ethnic minority elderly population.

National Institute of Allergy and Infectious Diseases

Although there is little evidence that AD is caused by a virus or other infectious agent, some of the symptoms and the brain damage seen in Alzheimer patients are strikingly similar to those of other viral diseases such as AIDS and scrapie. These similarities suggest that studies of viral diseases of the brain might shed light on the AD process.

At NIAID'S Rocky Mountain Laboratories in Hamilton, Montana, intramural scientists Drs. Bruce Chesebro and Richard E. Race and their colleagues have been studying scrapie, which is thought to be a viral disease although the agent that causes it has not yet been identified. Animals with scrapie develop brain plaques, formed from thread-like protein strands, which resemble the protein-laden plaques seen in the brains of AD patients. The major protein in the scrapie plaques is called prion protein (PrP).

Researchers have discovered that PrP is produced by normal as well as scrapie-infected brains but, for some unknown reason, in normal brains the protein doesn't clump into plaques. The same is true for the amyloid compound that comprises the brain plaques found in Alzheimer patients. (Amyloid is found in normal and Alzheimer's-diseased brains, but the protein only congregates into plaques in the diseased brains.) The investigators have been trying to uncover what scrapie-induced changes cause PrP to form plaques. Similar changes may induce the amyloid plaques seen in Alzheimer patients.

Last year, Drs. Race and Chesebro developed a laboratory system that enabled them to grow the scrapie agent in tissue culture. This was an important step because it has not been possible to purify the modified PrP from brain tissue. Their first studies failed to reveal any changes in the normal production of PrP in cultures of infected mouse brain cells. But recently, a more sensitive technique allowed them to identify an altered PrP that is resistant to enzymes and other substances that break down the normal form of the protein. The experiments suggest that PrP may be modified after it is synthesized.

Future studies using this new system are aimed at uncovering whatever triggers the production of resistant PrP, and the structural features that allow it to resist normal chemical breakdown.

National Center for Research Resources

Shared research facilities provided by the National Center for Research Resources (NCRR) support a variety of studies focused on AD. Recently grantees of the General Clinical Research Centers (GCRC) have had some success in the use of experimental treatments to improve the mental function of patients with the disease.

Medication Can Help Some Patients With Alzheimer's Disease

An experimental drug called physostigmine, which stimulates brain pathways that use the neurotransmitter acetylcholine, can improve mental function of some patients with AD, according to NCRR grantee Dr. Lindy E. Harrell and her associates at the University of Alabama GCRC at Birmingham. The GCRC research has shown that physostigmine treatment may be useful for about 40 percent of patients with the disease.

The grantees have evaluated the first 20 patients with mild-to-moderate AD who received physostigmine in a double-blind trial (a trial in which neither the physician nor the patient knows what treatment is being given). Compared to those taking placebos, eight patients taking the drug showed improvement both on an objective learning test and in subjective ratings by family or medical staff. Some of the patients who responded to physostigmine had only mild improvement in cognitive function while others showed a dramatic change. Family members often were able to tell when a patient was receiving physostigmine.

Combined Drug Therapy May benefit Some Patients

Using two drugs to stimulate separate pathways in the brain holds promise for treating some patients with AD, according to Dr. Kenneth L. Davis and his associates at the Mount Sinai School of Medicine. In preliminary studies, the grantees found that some patients who do not respond to physostigmine may show cognitive improvement when a drug that stimulates another pathway--the noradrenergic--is added.

The idea of using combined drug therapy is based on the hypothesis that between one-third to two-thirds of patients with AD may be affected by damage not only to the cholinergic brain pathways, which use the acetylcholine, but also from damage to noradrenergic pathways, which use another neurotransmitter, norepinephrine. In pilot studies, Dr. Davis and his associates administered physostigmine with clonidine or yohimbine, both of which stimulate noradrenergic neurons to patients with AD. In some of them, the combined therapy produced cognitive responses that did not occur with physostigmine treatment alone.

The grantees now are conducting studies with larger numbers of patients. They also plan to test other drug combinations that act on both pathways.

National Center for Nursing Research

Research on AD supported by the National Center for Nursing Research (NCNR) focuses on nursing techniques to improve home and institutional care of AD patients. Studies are also aimed at developing better ways to educate and assist family caregivers.

Mental Stimulation Techniques for Patients May Benefit Caregivers

Teaching family caregivers techniques to improve the functioning of the patient with AD may also help to reduce caretaker stress and make it easier for them to handle the patient. NCNR grantee Dr. Mary P. Quayhagen at the University of San Diego is testing mental stimulation techniques for these patients that family caregivers can practice at home.

The study will include 126 families with a member who has mild-to-moderate AD. Families will be divided into three groups. In an active mental stimulation group, family caregivers and patients will receive 1.5 hours of training and supervised practice a week in conversation, memory techniques, and problem solving. Caregivers will work with patients at home for five additional hours each week. In a passive mental stimulation group, caregivers will spend the same amount of time with patients, but practice such techniques as reading to the patient, which does not require active mental participation by the patient. A third group will not receive any training on stimulation techniques.

Participants in all groups will be evaluated during and after the 3-month training program for functional improvement in the patients and enhanced well-being in the caregivers.

Educational Package Will Teach Cognitive Assessment to Home Health Care Professionals

Most patients cared for by home care professionals are over age 65 and many have unidentified AD and related dementias--some of which are reversible. NCNR grantee Dr. Leonard Berg and his colleagues at the Washington University School of Medicine in St. Louis, Missouri, are developing an educational package to help nurses, social workers, and others who provide home care to conduct cognitive assessments in a skillful and consistent manner and to identify the need for further comprehensive evaluation. A videotape and written materials will include techniques for assessing a patient's memory, orientation, communication, functional abilities, attention, and judgment. The package also will cover strategies to help older persons overcome or compensate for problems in these areas.

As the population ages, home care services will take on greater importance. The success of home health care relies heavily upon the skills and independent judgments of these clinicians.

Videotape To Help Nurses Assess Psychiatric Symptoms in AD Patients in Long-Term Care

Although the cause of AD remains unknown, many scientists suspect symptoms may arise from a loss of cells that produce the neurotransmitter acetylcholine, a brain chemical crucial to memory formation. Levels of this important chemical may be decreased by 90 percent in people with AD.

In the search for better methods of diagnosis, NINDS intramural scientist Dr. Thomas N. Chase and his colleagues are studying the utility of single-photon emission computed tomography (SPECT) scans for measuring the density of receptors for acetylcholine. Receptors are proteins on the cell surface that recognize, and allow the cell to use, substances outside the cell. By injecting six AD patients, three Pick's disease (a disorder clinically similar to AD) patients, and seven healthy volunteers with an iodine-labeled compound, the investigators were able to locate the brain areas with the greatest abnormalities in these receptors. When compared with the healthy individuals, five of the six Alzheimer patients showed reduced receptor numbers in one brain region while the Pick's patients showed reductions in a different part of the brain. This indicates that SPECT may be useful in differentiating AD from Pick's disease.

At Beth Israel Hospital in Boston, Massachusetts, NINDS grantee Dr. Marek-Marsel Mesulam is studying physostigmine and tacrine (THA), two drugs that enhance transmission of acetylcholine by inhibiting its fast breakdown by enzymes known as cholinesterases. In studies of Alzheimer patients' brains, Dr. Mesulam found large amounts of two cholinesterases in the plaques and tangles, but relatively little in the remaining normal brain cells. However, the two drugs did more to inhibit the enzymes' activity in the normal brain cells than in the plaques and tangles. New drugs might be designed more to weaken the activity of plaque and tangle-bound enzymes than to enhance the transmission of acetylcholine. Dr. Mesulam also found that certain properties of the enzymes found in plaques and tangles were different from those of enzymes in normal cells--a discovery that may be useful in diagnosis of AD through brain biopsy or cerebrospinal fluid examination.

Genetic Clues Indicate Alzheimer's Disease May Have Several Causes

Recent studies by NINDS grantees and intramural scientists suggest that the condition we call AD may actually be a group of diseases with similar symptoms. About 60 percent of AD cases are sporadic, that is, only one person in a family is affected. When several members of a family are affected but in a random pattern, AD is said to be familial. Patients with this type, which accounts for about 30 percent of the cases, may have a genetic predisposition to AD such as receptor sites for environmental toxins. The remainder of the cases--less than 10 percent--are of the autosomal dominant type, in which people definitely have a gene for AD that is passed from parent to offspring for at least three generations, both sexes are affected equally, and an identifiable pattern is formed. NINDS intramural investigators Dr. Ronald Polinski and Linda Nee, working with 64 other members of the Familial Alzheimer's Disease (FAD) Collaborative Study group, reported that not all FAD can be linked to

chromosome 21, as had been suggested in earlier studies. A study of 48 FAD pedigrees indicated that age at disease onset seemed to be a key discriminant: families with a history of early onset (before age 65) had significant linkage to chromosome 21, while those with late did not. The scientists believe this strengthens the theory that AD may have more than one cause. Possible alternative causes include a gene or genes on other chromosomes, an environmental factor or factors, or a combination of both.

In another study of 70 FAD families, Dr. Polinsky, Ms. Nee, and their colleagues found that children of Alzheimer patients in these families had different likelihoods for developing the disease based on their parents' age at onset. People whose parents developed AD before age 58 had a 53 percent lifetime risk for getting the disease; those whose parents became ill after age 58 had an estimated 86 percent risk rate. Furthermore, men and women were equally likely to develop the disease in early onset groups, while female offspring had a slightly greater risk than males in late onset families. These data suggest that early onset AD may be primarily genetic. However, the 86 percent risk rate in late onset families indicates that something more than genetics is involved in those groups, perhaps an environmental factor.

AD patients make up the majority of long-term residents in nursing homes. In addition to severe cognitive and functional impairments, many have psychiatric symptoms such as hallucinations, delusions, depression, and agitated or combative behavior. Many nurses do not have training to assess and care for patients with psychiatric symptoms.

NCNR grantee Dr. Donald L. Price and his colleagues at The Johns Hopkins University School of Medicine are developing a videotape and manual to train nurses in long-term care facilities to assess and monitor the mental status of AD patients. A skilled assessment of psychiatric symptoms can enable nurses to plan care that will help moderate patients' disabilities, enhance their strengths, and provide maximum freedom.

The videotape will teach nurses to detect changes in mental status that may signal medical illness, and to document symptoms that may be the effects of mind-altering drugs and detect unwanted side effects. The videotape will help nurses understand the symptoms of depression, which is treatable in AD patients, or delirium, which can be life-threatening to the patient and a danger to staff. The videotape is also expected to provide very useful information to care providers such as social workers and physicians as well as to nurses.

Outlook

Research on AD so far has not yielded a definitive cause. Nevertheless, substantial progress has been made toward understanding some possible causes. The origins of the hallmark neuropathological features of AD, amyloid plaques and neurofibrillary tangles, are becoming increasingly clear. A major protein component of tangles has been shown to be a modified form of a protein involved in maintaining the shape of nerve processes. Amyloid deposition has been shown to result from improper processing of a normally occurring protein. Recent studies have also suggested ways in which the amyloid protein could be responsible for neuronal cell death, as well as ways in which this process could be therapeutically interrupted. Despite the absence of a clinical breakthrough, the goals of understanding the cause of the disease and discovering ways to treat or prevent it are more clearly in sight.

Depression And Behavior Problems Complicate The Clinical Picture

Not only is it difficult to diagnostically separate Alzheimer's disease from depression in the elderly, but many patients with Alzheimer's develop the added hardship of depression. Dr. Linda Teri of the University of Washington has implemented a behavioral treatment for depression by training family members in skills designed to decrease depression. One of the skills is to identify suitable pleasant activities and then engage the Alzheimer's disease patient in participation to improve mood as well as the interpersonal relationship between the patient and caregiver. It is noteworthy that depression was observed in over half of the caregivers of depressed Alzheimer's disease patients at the time they entered this study, suggesting that the task of dealing with both Alzheimer's disease and depression in the patient may put caregivers, themselves, at risk for depression.

Behavioral disturbances are frequently another complication of disease patients. When Alzheimer's patients manifest psychosis or agitation they are most often treated with neuroleptic medications--the same antipsychotic treatments used with psychiatric patients who suffer from hallucinations and delusions. A problem with neuroleptics is the risk of tardive dyskinesia (a condition characterized by involuntary jerky movements). Dr. Davangere Devanand at Columbia University is addressing the lack of adequate data on the effects and safety of neuroleptic medications used to treat these conditions in Alzheimer's patients. His study is assessing the efficacy and side effects of a traditional dose of oral haloperidol versus a low dose on: symptoms, activities of daily living and cognitive functioning.

Dr. Barry Rovner of Johns Hopkins University is implementing an intervention designed to reduce behavioral problems among demented patients in nursing homes. This randomized controlled clinical trial involves three components: 1) multi-disciplinary clinical visits directed by a psychiatrist; 2) administration of appropriate psychotropic drugs; and 3) an activities program designed just for the demented patients. This study has implications not only for Alzheimer's disease patients, but also for systems of care.

The Family

There is continuing evidence that the stress of caregiving is associated with health consequences. NIMH has placed particular emphasis on the area of family studies, and for several years has had in force an announcement soliciting grant applications for "Research on Family Stress and the Care of Alzheimer's Disease Victims."

NIMH is funding several projects focussing on the chronic impact of caregiving and the relationships between psychological distress and physical health. Previous results from Drs. Janice Kiecolt-Glaser and Ronald Glaser at Ohio State University, indicated that family caregivers of Alzheimer's disease patients

not only have increased rates of infectious illness and symptoms of clinical depression, but often suffer suppression of their immune systems. Ongoing studies are exploring how caregivers in different contexts--those caring for the patient at home, those caring for a patient in an institution, those who are recently bereaved--vary in immune function. Dr. Igor Grant at the University of California, San Diego is investigating whether neuroendocrine and immunologic variables may help distinguish successful from unsuccessful caregivers. This may help predict those who will themselves develop an illness.

At the Palo Alto Veterans Administration Medical Center, Dr. Dolores Gallagher is studying caregivers and has found the rate of anger reported was 67 percent, with depressed mood identified in 54 percent of caregivers. Dr. Gallagher has developed two interventions--one aimed at anger management and the other at depression. Pilot data show that the anger management intervention may be particularly effective in reducing clinical symptoms in caregivers. Researchers are also assessing the hypothesis that individuals who tend to hold their anger in may be at greater risk of experiencing cardiovascular disease.

An incidental finding from a study of neurotransmitter concentrations in the cerebrospinal fluid of Alzheimer's patients and controls demonstrated dramatic elevations of GABA (gamma-aminobutyric acid) in a segment of the control group --chronically stressed, yet well functioning, caregiver spouses. Dr. Nunzio Pomara of the Nathan Kline Institute and New York University found no concomitant increase in markers for other neurotransmitters such as dopamine, serotonin or norepinephrine. The meaning of these findings is unclear, and further research is called for to replicate the results and to determine the implications of the GABA elevations.

Dr. Leonard Pearlin at the University of California, San Francisco, is attempting to identify the range of stressors experienced by caregivers in conjunction with their access to and use of formal and informal supports. In another study, caregiving "careers" are being followed, in which new caregivers will be studied until death of the care recipients. Drs. Powell Lawton, Rachel Pruchno, and Ms. Elaine Brody, of the Philadelphia Geriatric Center, will study these careers for the impact of family dynamics, length of caregiving, and personal characteristics of the caregivers. Another factor being assessed is daughter's marital status in a subgroup of caregiving daughters of widowed, impaired older parents.

Services Research And Systems Of Care

NIMH continues to solicit grant applications on "Mental Illness in Nursing Homes." Projects currently funded include attention to such issues as work stress and morale of nursing home employees, and the effect of staff expectations on residents' functional status. The care of the elderly residing in personal care homes, a type of facility where increasingly many mentally

ill elderly are found, is being examined at the Community Services Institute in Narberth, Pennsylvania. Personal care homes have not traditionally provided mental health care, and Dr. Leonard Gottesman is studying strategies for improving care of mentally ill residents of such homes, as well as their cost effectiveness, since these facilities are replacing large state hospitals as homes for the mentally ill.

A currently funded service demonstration project is evaluating the effectiveness of providing trained respite care workers to caregiving families of Alzheimer's disease patients, in terms of both improvements in the families' quality of life and reductions in the patients' institutionalization rates. Another project is evaluating a model program for elderly persons disabled with Alzheimer's disease or other chronic mental disease, which encompasses individual assessment and treatment planning, case management, and supported referral. Patients in the program are being compared with controls in terms of their functioning, maintenance of residence in natural community settings, services utilization, mortality and morbidity rates, and quality of life.

Training Of Research And Clinical Personnel

NIMH has developed a Research Teacher/Investigator award program called the Geriatric Mental Health Academic Award program, with 10 awards presently being supported for seven psychiatrists and three nurses. In addition, two young investigators are supported by Research Scientist Development Awards in their study of the etiology, pathogenesis and diagnosis of Alzheimer's disease. NIMH also supports a three-part clinical training program in Mental Health and Aging which focuses a portion of the curricula on Alzheimer's disease. Sixteen awards to various mental health disciplines are presently being funded: 4 individual faculty scholar awards, 4 institutional clinical training grants for minority students, and 8 institutional clinical training grants for general training.

Educational Materials And Information Dissemination

NIMH has an active information dissemination program on Alzheimer's disease. Efforts include distribution of the Fact Sheet on Alzheimer's Disease written especially for families, and dissemination of research findings to the field. The Fact Sheet has recently been updated, and the new version is now available.

In March 1990, NIMH held a workshop on the "Mental Health of Family Caregivers in Alzheimer's Disease and related Dementias," in which leading researchers discussed current findings and future research needs regarding the interaction between physical and mental health in Alzheimer's disease caregivers, intervention strategies with families of Alzheimer's disease patients, and mental health services that take cognizance of family issues in Alzheimer's disease. A forthcoming volume based on this workshop will further define and foster new directions in services research on Alzheimer's disease.

Papers from a 1989 NIMH conference on "Age and the Organic Syndrome of Delirium" are also being prepared for publication. At this conference, investigators and clinicians discussed advances in assessing and understanding states of delirium in the elderly, identified current research needs, and considered changes in diagnostic nomenclature that may assist in improving medical diagnosis and treatment of states of delirium. Syndromes of delirium are frequently superimposed on demented patients's basic cognitive deficits, and often reflect underlying conditions that tend to be life-threatening, such as concurrent medical disorders or pharmacological toxicity.

The Future

Council And Advisory Panel On Alzheimer's Disease

NIMH currently provides the Deputy Executive Secretary and staff support for the Department of Health and Human Services' Council on Alzheimer's Disease and the Advisory Panel on Alzheimer's Disease, both of which were established by P.L. 99-660. The Council is composed of Federal employees, while the Panel is a non-Federal advisory body appointed by the Office of Technology Assessment. The Council coordinates basic research on brain and behavior, epidemiology, diagnosis, treatment, costs, and financing and is charged with the responsibility for an annual report to Congress detailing progress in basic and clinical research on Alzheimer's disease. In 1990, the Council also assembled and distributed a detailed compilation of all the research projects, demonstrations and other activities on Alzheimer's disease and related dementias funded by its member agencies.

The Advisory Panel in 1989 published its first of four Congressionally mandated reports, in which it set forth recommendations for legislative and administrative actions to improve services for patients with Alzheimer's disease and related dementias and their families. It also set forth recommendations on how to provide for promising biomedical research on this disease. The Panel's second report updates topics covered in the earlier report, such as biomedical and services-oriented Alzheimer's disease research, financing of care, and eligibility for services, and addresses the special topics of personnel and training issues in the care of Alzheimer's disease victims.

As a major emphasis of its "Decade of the Brain" programs, NIMH will stimulate additional research on Alzheimer's disease in an effort to answer many of the puzzling questions surrounding the disease and to determine the best treatments and services possible. Future directions of Alzheimer's disease research at NIMH include: 1) the molecular genetics of Alzheimer's disease; 2) biochemical analyses of the neuropathological characteristics that define Alzheimer's disease--neurofibrillary tangles and amyloid plaques; 3) the role of nerve growth factors in Alzheimer's disease and the potential use of neural implants as a

research tool; 4) identification of diagnostic markers for Alzheimer's disease --particularly markers useful at early stages of the disease--including peripheral biological markers, and/or behavioral, electrophysiological, or radiological indices; 5) further investigation with brain imaging techniques, such as positron emission tomography (PET) and magnetic resonance imaging (MRI), to study changes in brain structure and metabolism in Alzheimer's patients; 6) refinement of diagnostic procedures for Alzheimer's disease; 7) improved understanding of the pathogenesis and course of psychiatric and behavioral symptoms in Alzheimer's disease; and 8) evaluation of strategies for clinical intervention in Alzheimer's disease, including behavioral and psychopharmacological techniques for managing symptoms or arresting cognitive decline, and interventions and services for supporting family members and alleviating caregivers' stress.

Arthritis and Related Musculoskeletal Disorders

	Obligations				
	1988 Actual	1989 Actual	1990 Actual	1991 Estimate	1992 Estimate
National Institutes of Health:					
National Institute of Arthritis and Musculoskeletal and Skin Diseases.....	\$67,849,000	\$71,218,000	\$71,288,000	\$80,323,000	\$84,241,000
National Cancer Institute.....	1,290,000	1,377,000	1,398,000	1,476,000	1,531,000
National Heart, Lung, and Blood Institute....	953,000	636,000	486,000	515,000	550,000
National Institute of Dental Research.....	8,791,000	9,099,000	6,037,000	6,523,000	7,011,000
National Institute of Diabetes and Digestive and Kidney Diseases....	7,750,000	8,140,000	15,000,000	15,600,000	16,700,000
National Institute of Neurological Disorders and Stroke...	2,837,000	2,608,000	2,441,000	2,563,000	2,742,000
National Institute of Allergy and Infectious Diseases.....	20,105,000	24,503,000	20,241,000	21,885,000	23,905,000
National Institute of General Medical Sciences.....	458,000	247,000	250,000	250,000	250,000
National Institute of Child Health and Human Development.....	1,397,000	1,813,000	1,254,000	1,400,000	1,500,000
National Eye Institute.....	---	695,000	1,328,000	1,381,000	1,436,000
National Institute on Aging.....	2,968,000	3,492,000	3,382,000	3,558,000	3,728,000

Arthritis and Related Musculoskeletal Disorders

	Obligations				
	1988 Actual	1989 Actual	1990 Actual	1991 Estimate	1992 Estimate
National Center for 1/ Research Resources....	5,164,000	5,070,000	4,306,000	4,038,000	3,573,000
National Center for Nursing Research.....	141,000	227,000	621,000	750,000	800,000
Office of the Director. ^{2/}	167,000	205,000	212,000	---	---
Total, NIH.....	119,870,000	129,330,000	128,244,000	140,262,000	147,967,000
Agency for Health Care Policy and Research...	---	---	3,034,851	3,501,000	3,501,000
Total PHS.....	119,870,000	129,330,000	131,278,851	143,763,000	151,468,000

/ This includes RCMI awards. Prior to FY 1989, RCMI's were shown in OD.

2/ This includes AREA awards for FY 1988 - 1992, and RCMI awards for FY 1988.

NATIONAL INSTITUTES OF HEALTH

National Institute of Arthritis and
Musculoskeletal and Skin Diseases

ARTHRITIS, RHEUMATIC DISEASES, AND RELATED DISORDERS

The term "arthritis" encompasses a large family of over 100 so-called rheumatic diseases which affect the joints and connective tissues that support the skeleton and the body such as muscles, tendons, and ligaments, and that protect and cover internal organs.

Although the overall prevalence of rheumatic diseases increases with age, many may affect young adults and children. About one in seven Americans, or as many as 37 million, suffer from some form of rheumatic disease. At least 24 million more have the bone disease osteoporosis, and there are many others with musculoskeletal disorders such as knee and back problems. The annual economic impact of these disorders is estimated at \$9 billion for arthritis, \$6 billion for osteoporosis, and \$16 billion for back pain. As the population ages, these expenditures will continue to increase. By the year 2,000, the estimated annual cost for all Musculoskeletal diseases is projected to be \$95 billion.

Research can provide ways to prevent disease and disability and thereby reduce these expenditures. For example, a long-term clinical trial by NIH intramural scientists found that patients with lupus nephritis (a life-threatening kidney disease) who were treated with a combination of cytotoxic drugs (ones that inhibit or kill cells) and steroids had a significant improvement in kidney function and increased longevity. An NIAMS analysis has shown that the combined treatment, now an accepted practice, cost a total of \$9.8 million to develop over 18 years, but may save the Nation as much as \$93.1 million each year in medical and associated economic costs.

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) leads and coordinates the Federal biomedical research effort against the many forms of arthritis and related disorders. Other NIH components that support research in this area include the National Cancer Institute (NCI), the National Heart, Lung, and Blood Institute (NHLBI), the National Institute of Dental Research (NIDR), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Allergy and Infectious Diseases (NIAID), the National Institute of General Medical Sciences, (NIGMS), the National Institute of Child Health and Human Development (NICHD), the National Eye Institute (NEI), the National

Institute on Aging (NIA), and the National Center for Research Resources (NCRR) and the National Center for Nursing Research.

Although medical science has yet to find a cure for many forms of arthritis and related disorders, significant progress has been made through basic and clinical research conducted both in NIAMS intramural laboratories and, through NIAMS support, in research settings throughout the country.

Clues Found to Genetic and Occupational Factors in Osteoarthritis

Degenerative joint disease or osteoarthritis (OA), the most common form of arthritis, afflicts more than 16 million Americans. This disease primarily affects cartilage, the protective material that covers and cushions the ends of bones, causing it to fray, wear, ulcerate, and, in extreme cases, disappear entirely, leaving a bone-on-bone joint. At the edges of the joint, bony spurs may form. Disability results most often from disease in the knees, hips, and spine. In most patients, no cause of the disease can be readily identified.

For the first time, a gene has been found that causes a rare form of osteoarthritis. Researchers led by NIAMS grantee Dr. Darwin J. Prockop at Thomas Jefferson University in Philadelphia, Pennsylvania, and Dr. Roland W. Moskowitz at Case Western Reserve University in Cleveland, Ohio, studied three generations of a family affected with a form of primary osteoarthritis. They pinpointed a gene defect in collagen II, a structural protein that strengthens cartilage. The researchers found a single gene mutation that directs the substitution of one amino acid, cysteine, for another, arginine, at one position in the chain of more than 1,000 amino acids that make up collagen II. This finding strongly supports the idea that a single genetic flaw can cause at least one form of OA, and maybe others.

Other factors, such as certain occupations that require frequent knee bending, may also cause osteoarthritis in overused joints. Researchers led by Dr. David Felson at Boston University in Massachusetts, looked at the link between the physical demands of a job and subsequent development of knee OA in the Framingham Study, a long-term epidemiologic study of a large population-based group with diverse occupational histories. The researchers found that men whose jobs required knee bending and heavy physical activity had more than twice the risk of later developing OA in the knee than men whose jobs did not require either activity. The researchers conclude that physical demands of the job are important risk factors for OA, and working conditions may need to be modified to reduce stress to the knees.

Genetic and Therapeutic Diversity Revealed in Patients with Rheumatoid Arthritis

A chronic inflammatory disease of unknown cause, rheumatoid arthritis (RA) afflicts more than 2 million Americans, and it affects twice as many women as men. The primary target of this major crippling disorder initially is the synovium or joint lining. This tissue, which normally is smooth and shiny, becomes inflamed, painful, and swollen. Rheumatoid arthritis can also produce such general symptoms as weakness, fatigue, and loss of appetite, and it can also affect other parts of the body such as the blood vessels. The disease tends to be both chronic and irregular and is frequently disabling. The cause of the disease involves both genetic and nongenetic factors.

Many patients with RA have a specific genetic tissue marker called HLA-DR4. However, not everyone who has this marker develops the disease. Previous studies have found that most Caucasian Americans with RA share one of two subsets of HLA-DR4 called DW4 or DW14.

Grantee Dr. Gerald T. Nepom and colleagues at the Virginia Mason Research Center and the University of Washington Medical School both in Seattle, studied these subset markers in order to determine the factors needed to develop RA. They found that 30 percent of the HLA-DR4 patients with adult and juvenile rheumatoid arthritis had the DW14 gene, while the other HLA-DR4 patients had either DW4 alone or both the DW4 and DW14 gene. The researchers found that DW4 and DW14 had the same immunologically active molecule on their surfaces, that is, they may provoke an immune response in the same way. An analysis of these markers could be used to test for the genetic differences in RA. In addition, these studies suggest that a double dose of the genes that make one susceptible to RA may contribute to its earlier onset.

An ideal treatment for rheumatoid arthritis and other autoimmune disorders would be a nontoxic means of neutralizing immune cells responsible for the disease. Researchers led by Dr. Irun R. Cohen at the Weizmann Institute of Science in Rehovot, Israel, induced adjuvant arthritis (a disease that resembles human RA) in rats and then made preparations of a population of immune cells--T cells--obtained late in the course of the disease. After treatment with substances that cause the cells to multiply, the cells from the diseased animals were used to inoculate disease-free rats. The rats proved to be resistant to adjuvant arthritis. This successful activation of "primed" T cells from diseased animals is a key step in achieving the next goal: development of studies for T cell therapy and vaccination in humans.

Factors in Spread of and Susceptibility to Lyme Disease Investigated

A complex disorder, Lyme disease was first identified in 1975 by NIAMS grantee Dr. Allen C. Steere, now at Tufts-New England Medical Center in Boston. The disease is caused by a tick-borne spirochete (a form of bacteria), Borrelia burgdorferi, which was isolated in 1982 by Dr. Willy Burgdorfer at NIAID. The tick is often found on deer and mice. However, migrating birds that may travel up to 7,000 miles from their summer breeding grounds to their winter quarters may also harbor the tiny ticks.

Researchers led by NIAMS grantee Dr. Russell C. Johnson at the University of Minnesota in Minneapolis examined over 9,200 individual birds representing 99 species from a Lyme disease-endemic area in Minnesota and Wisconsin. In a 1-year period, they found 250 larvae and young ticks on 58 birds in 15 of the species examined. Fifty-six of these birds tested positive for the Lyme disease spirochete. It is estimated that 10 billion birds migrate seasonally across the United States. These findings suggest that birds may be both an important local reservoir and a long-distance dispersal agent for B. burgdorferi-infected ticks to other regions of the country.

Although Lyme disease can involve many tissues of the body, including the skin, joints, heart, and nervous system, one feature is chronic joint inflammation that may resemble rheumatoid arthritis. Although most patients with Lyme arthritis respond well to prompt treatment with antibiotics, some do not. Regardless of the antibiotic used and the duration of treatment, these patients continue to have chronic arthritis.

Dr. Steere and Drs. Edward Dwyer and Robert J. Winchester at New York University's Hospital for Joint Diseases studied 130 patients with various forms of Lyme disease and 86 healthy individuals. They found that patients with chronic arthritis were genetically different from those with arthritis of short or moderate duration. Of the 80 patients with arthritis, 57 percent of those with chronic arthritis (28) had a specific genetic marker, HLA-DR4, compared with only 23 percent of those with arthritis of moderate duration (30) and only 9 percent of those with arthritis of short duration (22). HLA-DR4 is also associated with susceptibility to rheumatoid arthritis. The researchers said that the presence of HLA-DR4 was significantly associated with the failure of antibiotic therapy. This work is also supported by the NIAID.

Defect in T Cell Found in Patients with Juvenile Arthritis

More than 200,000 American children are afflicted with some form of arthritis. One of these diseases, juvenile rheumatoid arthritis (JRA), like adult RA, is a chronic inflammatory disease of unknown cause that is characterized by arthritis and apparent defects in regulation of the immune system.

Researchers led by Dr. Edgar G. Engleman at Stanford Medical School in California may have identified one such defect in an immune cell known as a suppressor T cell. The researchers purified T Cells from 24 patients with active or inactive JRA, five patients with cystic fibrosis (a chronic, inherited disease), and nine healthy matched controls. The T cells were treated with histamine or concanavalin A, agents known to activate suppressor T cells. The researchers found that cells from 12 of the 13 patients with active JA showed abnormal suppressor T cell function. In contrast patients with inactive JRA and CF had normal T suppressor cell function. These results suggest that patients with clinically active JRA have a reversible defect in T suppressor cell function. The response of cells to histamine, rather than concanavalin A, appeared to be a more sensitive indicator of defective suppressor cell function.

Clinical Assessment Methods, Risk Factors for Lupus Examined

Systemic lupus erythematosus (SLE) predominantly affects women of childbearing age and is three times more common in Blacks than in whites. In lupus, the body produces abnormal antibodies that react against the patient's own tissues for reasons still unknown. In its systemic form, lupus can affect many systems of the body including the heart, lungs, kidneys and central nervous system.

The judgment of whether a patient with SLE has more or less active disease is an important factor in monitoring the effects of treatment on patients. At the present time, more than 60 systems have been developed to evaluate disease activity. This lack of standardization is an impediment to the clinical evaluation of disease activity in SLE patients.

NIAMS grantee Dr. Matthew H. Liang and his colleagues at Brigham and Women's Hospital in Boston, Massachusetts, tested six systems used to evaluate gradations of disease activity in SLE for their ability to pick up small changes and their reproducibility. For 1 month the researchers studied 25 SLE patients with a range of disease activity. All six clinical assessment scales performed well when compared with physician judgments and enabled them to quantitate, to some extent, disease activity. Three of the assessment scales, however, were more reproducible and sensitive to changes in the clinical state. In addition, patient's self-reported

evaluation of disease activity correlated highly with the physician's assessment.

The low survival rate for Black patients with SLE has been the subject of much discussion. Drs. John Reveille at the University of Texas Health Science Center in Houston and Graziela S. Alarcon at the University of Alabama in Birmingham studied 389 American Black and white lupus patients, both male and female. The researchers found that being an American Black, being older at onset, and having thrombocytopenia (low blood platelet count) were each independent risk factors for a worse prognosis. In addition, all patients with kidney disease fared worse than those without it. American Black women with SLE had a lower life expectancy than White women with the same disease. Men and women did not differ in survival rates. These studies should help focus research on ways to improve survival rates in all populations, and particularly in Blacks.

Animal Model Points to Genetic Cause of Ankylosing Spondylitis

Ankylosing spondylitis one of a family of arthritic diseases called the spondyloarthropathies, that primarily affect spinal joints, can lead to stiffening or fusion of the spine. This family of diseases affects hundreds of thousands of young adults and children. Researchers have known for several years that there is a strong association between these diseases particularly ankylosing spondylitis and the genetic marker HLA-B27. Research has suggested that infections may play a role in these diseases.

A new animal model has shown, however, that the HLA-B27 gene may itself cause these diseases. Drs. Joel D. Taurog and Robert E. Hammer at the University of Texas Southwestern Medical Center in Dallas, Texas, have used transgenic technology (insertion of foreign genes into an animal's developing egg) to produce two strains of inbred rats that have functional human genes for HLA-B27. These transgenic rats developed a range of symptoms strikingly similar to those of the spondyloarthropathies, including inflammation and destructive changes of the spine, large joints, bowel, skin and other organs. The researchers said that future studies in the rat model will help them determine if an infectious agent is necessary to work with the HLA-B27 gene to cause disease. This work was also supported by NCRP.

Roles of IL-1 and Calcium Absorption in Osteoporosis

In osteoporosis ("porous bone") bone mass decreases, making bones more susceptible to fracture. It has been estimated that osteoporosis is estimated to cause more than

1.3 million bone fractures yearly in postmenopausal women and in elderly persons in general.

An international conference, "Research Advances in Osteoporosis," cosponsored by NIAMS, NIA, NIDDK, the National Osteoporosis Foundation, and the American Society for Bone and Mineral Research, was held in February 1990. The conference reaffirmed the effectiveness of estrogen replacement therapy in reducing postmenopausal bone loss.

Osteoporosis occurs when sufficient bone tissue has been lost to make the person susceptible to fractures. A variety of risk factors have been identified, including age and menopause. Recent research has shown that the bone loss may be attributable to a defect that causes excessive bone resorption. Previous studies have shown that patients with osteoporosis secrete more interleukin 1 (IL-1), a potent stimulator of bone resorption than others with inactive or no disease.

NIAMS-supported investigators led by Dr. Louis V. Avioli at the Jewish Hospital of St. Louis, Missouri, found that menopause heralds a marked increase in IL-1 production that is suppressed by estrogen replacement therapy. Thus monitoring IL-1 activity may be a useful method to assess the risk of developing osteoporosis and to determine the best candidates for estrogen therapy.

Much emphasis has been placed on increasing the recommended daily calcium requirement, particularly in women, as a preventive measure for osteoporosis. Dr. Robert Heaney and his colleagues at Creighton University in Omaha, Nebraska, over a 23-year period, studied calcium absorption in a group of Catholic nuns, all of whom were active and in good health. Most of them were studied two to four times at 5 year intervals. The women were admitted to the hospital for 1 week and given a diet that replicated the amount of calcium that they normally consumed based on a 1 week record. The researchers used two methods to measure absorption. With the first, they were able to trace the movement of calcium in and out of the intestine. With the second method, they could compare the amount of calcium taken in to that excreted. The researchers found that the efficiency with which calcium is absorbed decreases with age and loss of estrogen at menopause. The investigators estimate that as a woman ages absorptive efficiency of calcium decreases by 20 to 25 percent. The researchers said that some individuals can respond to low intakes of calcium quite adequately while others, equally healthy, respond very poorly.

Role of Growth Factor in Fracture Healing Revealed

In many cases, a broken bone is slow to heal or may not repair itself at all. For such individuals, no definitive

therapies have emerged. Fracture healing involves a complex, tightly regulated cascade of biological events. Four distinct phases are generally recognized and several systemic and local factors may be involved in the regulation of fracture healing. Studies have shown that one such factor may be transforming growth factor beta (TGF-B), which has been shown to regulate bone remodeling, a related process by which bone tissue is constantly being replaced and maintained.

NIAMS intramural researcher Dr. Mark Bolander and colleagues studied fracture healing in a rat model for 28 days. The fracture repair region was dissected into soft and hard callus portions. (Callus is tissue that forms to cover the ends of fractured bone). Using recombinant DNA techniques, the investigators probed for intracellular and extracellular forms of TGF-B over several weeks and found that it was present in both hard and soft callus portions.

The researchers concluded that TGF-B is present during the three critical cellular events of fracture healing: initiation of repair, chondrogenesis (proliferation of cells that produce cartilage), and bone formation. "Knowledge of the repair process should lead to possible clinical intervention when the natural repair system is ineffective."

Physical Strength Unrelated to Back Disorders

Back pain is a common and costly condition that often originates in the workplace. Prevention has focused on improving physical factors such as strength, endurance, and flexibility, based on the assumption that weaker individuals are more likely to have back problems.

Researchers led by Dr. Stanley J. Bigos at the University of Washington in Seattle studied more than 3,000 male and female workers in an aircraft manufacturing plant. These individuals, who had no prior history of back surgery, back pain, or cardiovascular problems, were asked to perform three isometric tests: torso lift, arm lift, and leg lift. The researchers found that women had between 52 percent and 65 percent of the strength of men in the three tests. The arm strength of women remained constant at all ages but the other three strength measures declined with age. When the researchers examined each isometric lift separately as a predictor of reported back pain, subjects with greater strength were at higher risk than were weaker workers. However, after age was taken into consideration, no significant correlation remained, and there were no differences between men and women in the incidence rates of back problems.

Research Highlights Risks and Benefits of Exercise

Increased participation in physical fitness and sports programs has caused great concern about athletic injuries such as partial or complete rupture of the anterior cruciate ligament (ACL). This is a fibrous band of tissue in the center of the knee that connects the thigh bone to the shin bone. ACL is the primary support structure of the knee for pivoting and jumping but is also important for less stressful activities.

Analysis of gait, or walking, can be used to detect subtle differences in function, and therefore can be useful for evaluating patients who have a knee injury. Dr. Thomas P. Andriacchi and his colleagues at Rush-Presbyterian-St. Luke's Medical Center in Chicago, Illinois, evaluated 16 patients who had a deficiency of the ACL and 10 others whose ACLs were normal. While the subject walked, jogged, and ascended and descended stairs, the researchers recorded all aspects of motion and forces in the hips, knees, and ankles.

They found a substantial difference between the groups. To avoid contracting the quadriceps muscle (the one located in front of the thigh that controls flexation in the knee) patients with ACL injuries stiffened the knee during level walking and jogging but not when descending stairs. According to the researchers, this abnormal movement causes changes and problems in knees in which a ruptured ACL was never repaired or reconstructed.

With growing national interest in exercise and fitness, new efforts are being directed toward understanding the response of the body to various forms of exercise training. Researchers led by Dr. Harry K. Genant at the University of California, San Francisco, studied three groups of young men in order to identify the factors associated with greater bone density, 20 were nationally ranked water polo players, 19 were engaged in weight-training, and 20 subjects were nonexercisers. New techniques such as quantitative computer tomography were used to measure bone density in the spine. Dual photon absorptiometry (DPA) was used to determine hip bone density. The researchers found a significantly greater bone density among highly trained athletes compared with subjects of similar age. This was the first study to use DPA and reach this conclusion. In addition, the researchers found a significant association of muscle size with bone density in the spine and in the hip. This research reinforces the concept that, along with its other benefits, exercise can contribute to bone density.

National Cancer Institute

The National Cancer Institute (NCI) contributed to advances in arthritis research through studies of new growth of blood capillaries, which is characteristic of both rheumatoid arthritis and cancer.

In healthy adults, the growth of new capillaries, or angiogenesis, usually occurs only during wound repair, the menstrual cycle, and the formation of the placenta. Rheumatoid arthritis, diabetic retinopathy, tumor growth and metastasis (spread), and other related disorders are often associated with angiogenesis. Therefore, understanding its mechanism and finding ways to safely inhibit the process may lead to the development of new treatments for these diseases.

Synthetic Compound Helps Scientists Purify Growth Factor

In 1989, NCI grantee Dr. Judah Folkman and colleagues at the Harvard Medical School and Children's Hospital in Boston, Massachusetts, discovered a new synthetic compound that, when combined with certain steroids, inhibited angiogenesis 100 to 1,000 times better than another combination (heparin/steroid) used for this purpose. Like heparin, the synthetic compound, beta-cyclodextrin tetradecasulfate, does not inhibit new capillary growth by itself but acts as a carrier, transporting inhibiting agents such as steroids to the cells that line blood vessels.

This year, Dr. Folkman and his colleague, Dr. Yuen Shing, determined that beta-cyclodextrin tetradecasulfate also could substitute for heparin in purifying fibroblast growth factor (FGF), a hormone-like protein, employed by certain cancer blood vessels, that stimulates tumor growth. The researchers found that FGF has a strong affinity for both beta-cyclodextrin tetradecasulfate and copper. They used a combination of the two to extract large amounts of FGF that were twice those obtained by extraction with heparin, greatly facilitating future research on FGF.

National Institute of Dental Research

The National Institute of Dental Research (NIDR) supports a wide range of projects related to arthritis, including studies on modulating pain, on reducing inflammation, and on factors involved in the development of rheumatoid arthritis and osteoarthritis.

Roles of Growth Factors and Stress Explored in Inflammation and Restoration of Cartilage

In a rat model of RA, the joint becomes filled with immune cells (monocytes) recruited there to engulf the foreign inflammatory material and rid it from the body. Monocytes, however, also produce factors that contribute to pain and swelling, as well as enzymes that can destroy joint tissue. Recent studies by NIDR intramural scientists Drs. Sharon Wall, May Brandes and Janice Allen have shown that when the animals were injected with a hormone-like compound, transforming growth factor beta (TGF-beta), there was marked reduction in the inflammatory response. They found that TGF-beta suppressed recruitment of immune cells to the joint, thus limiting the number of monocytes present. TGF-beta also inhibits the activity of IL-1, a molecule that stimulates production of tissue-destroying enzymes. These findings point to this growth factor as a potentially important agent in treating chronic, inflammatory diseases.

Laboratory research by NIDR intramural investigators Drs. Teresa Morales and Vincent Hascall indicates that at least two growth factors are involved in maintaining the ability of cells to restore the structure and composition of cartilage, the resilient, fibrous tissue that protects the ends of the long bones. This repair and maintenance process fails during osteoarthritic degeneration. Their studies show that both insulin-like growth factor 1 and TGF-beta are critical to the ability of cartilage cells to maintain cartilage tissue. It is likely that at least some forms of osteoarthritis involve derangement in this finely tuned regulatory process. The next step is to determine how defective cells might be induced to produce these important regulators.

New evidence from NIDR intramural scientists Drs. Ronald Dubner and Maryann Ruda suggests that persistent pain associated with inflammation, as in RA, or nerve injury can lead to alterations in nervous system and immune function that can exacerbate disease processes. These changes may account for the heightened sense of pain experienced by chronic pain patients and the spread of the sensation beyond the area affected by disease or injury. Other research has shown that tumor growth and invasiveness are enhanced in animals exposed to painful stressors compared with control animals.

National Institute of Diabetes and
Digestive and Kidney Diseases

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has primary responsibility for support of endocrine research and thus has a pivotal role in supporting research on bone-active hormones and their cell receptors, especially in osteoporosis.

Role of Parathyroid Hormone in Treating Osteoporosis Examined

Parathyroid hormone (PTH) is the main hormone that regulates calcium resorption from bone. NIDDK grantee Dr. John Potts and colleagues at Massachusetts General Hospital in Boston have developed techniques to produce recombinant human PTH, which will allow altered forms of PTH to be synthesized. Studies correlating structure and function of these altered hormones will increase the understanding of PTH function and potentially create hormone analogs with therapeutic efficacy. Because PTH affects bone formation as well as resorption, analogs with more restricted effects may ultimately have value in treating osteoporosis.

NIDDK grantee Dr. Robert Lindsay at the University of Pittsburgh in Pennsylvania has just begun an exciting clinical trial to determine whether a fragment of PTH is effective in stimulating new bone formation in women with osteoporosis. Several groups of researchers are intensively studying PTH receptors to determine whether there are distinct receptors or second messenger pathways that account for the wide variety of cellular responses to PTH. These studies could lead to the development of different analogs that have selective actions.

National Institute of Neurological Disorders and Stroke

The National Institute of Neurological Disorders and Stroke (NINDS) supports research to advance understanding of the role of the nervous system in arthritis. Substantial evidence implicates the nervous system as an important contributor to arthritis damage.

Animal Studies Suggest Tissue Implants Alleviate Arthritis Pain

Pain control is a significant issue in the management of patients who have arthritis. NINDS grantee Dr. Jacqueline Sagen at the University of Illinois in Chicago has been studying the effects of adrenal tissue implants on pain sensitivity in arthritic rats. She found that arthritic rats with adrenal implants do not show the retarded weight gain normally associated with the disease model, and that the rats with implants have reduced vocal responses to pain stimulation when compared to arthritic rats without implants. Dr. Sagen's preliminary results have also shown that rats with implants do not develop the tolerance to the pain-killer morphine that normally occurs over time. In fact, morphine's effect appears to be enhanced by adrenal implantation. These results suggest that adrenal implants may be of value in alleviating the chronic pain associated with arthritis.

National Institute of Allergy and Infectious Diseases

The National Institute of Allergy and Infectious Diseases (NIAID) conducts and supports research in the diagnosis, treatment, and prevention of Lyme disease and other infectious diseases that result in arthritis.

New Diagnostic Test Being Developed for Lyme Arthritis

NIAID scientists Drs. Patricia A. Rosa and Tom G. Schwan of NIAID's Rocky Mountain Laboratories in Montana developed a sensitive new test that can detect small numbers of the spiral-shaped bacterium that causes Lyme disease. The scientists modeled their new test on PCR (polymerase chain reaction), a procedure that uses two short pieces of DNA, called primers, to define and bind the ends of a larger target segment of DNA being sought in a sample specimen. If the primers ferret out their target, an enzyme (polymerase) copies it. Repeated cycles of this search-and-copy process can generate billions of copies of the target DNA within a few hours.

PCR's extreme sensitivity gives it the advantage of detecting Lyme disease far earlier than conventional blood tests. These blood tests detect antibodies to B. burgdorferi, but the antibodies may be undetectable for up to 6 months after transmission of B. burgdorferi from an infected tick, and some people do not develop detectable levels of antibodies at all.

Before this diagnostic test can be used widely, scientists must first determine whether there is one human tissue that always harbors the bacterium when a person is infected and to which they can target the test. Otherwise, false negative results could occur.

Immune System Abnormality Found in Some JRA Patients

Dysfunction of the immune system is believed to play a key role in the development of juvenile rheumatoid arthritis (JRA). Using monoclonal antibodies, NIAID grantee Dr. Dorothy Lewis and her colleagues at Baylor College of Medicine in Houston, Texas, found that most patients with JRA demonstrated a marked increase of B cells (cells that produce antibodies in response to foreign proteins or antigens) in the blood. However, in one group of JRA patients, B cells were unresponsive to additional stimulation, indicating a functional abnormality. B cell antibody production and function are normally regulated by other white blood cells known as T cells, which were also found to be abnormal in one group of patients with JRA. The researchers concluded that abnormal B cell production in this subset of JRA patients may be due to an increase in a particular subset of T cells thought to be responsible for suppressing B cell activity.

National Institute of Child Health
and Human Development

The National Institute of Child Health and Human Development (NICHD) is studying the effect of sex steroids on the immune system. Steroids influence immune responsiveness and the course of autoimmune diseases, which are more common in women of reproductive age.

Oral Contraceptives May Protect Against Rheumatoid Arthritis

Rheumatoid arthritis has been reported to occur less frequently among women who have used contraceptive steroids. The role of sex hormones in the etiology of this disease has been suspected because of its greater frequency in women and because pregnancy improves RA symptoms.

NICHD is currently supporting a large study of the risk of rheumatoid arthritis in current and past users of oral contraceptives (OC). Headed by Dr. Thomas Koepsell at the University of Washington in Seattle, this study seeks to identify whether use of oral contraceptives can reduce the lifetime risk, or at least delay the onset, of RA. A preliminary finding is that there is an increased incidence of infertility among women who later develop RA. This finding supports the contention that RA is sensitive to the hormonal environment. Further preliminary analyses indicate that current OC use protects users against development of RA and that pregnant women have a lower risk of RA than nonpregnant woman. Past OC use and post-menopausal hormone therapy do not appear to affect the incidence of RA.

National Institute on Aging

The National Institute on Aging (NIA) supports biomedical, social, and behavioral research and training that relate to aging processes, specific diseases common in old age, and other special needs and problems of the older population.

Fat Distribution Not Linked to Osteoarthritis

NIA grantee Dr. Maradee A. Davis and colleagues at the University of California in San Francisco have found that while obesity is associated with osteoarthritis in the knees, feet, and hands, the specific distribution of fat on the body does not appear to be associated with the disease. In order to study the association of obesity with osteoarthritis, the investigators analyzed data from the U.S. Health Examination Survey I (HES I) and the National Health and Nutrition Examination Survey (NHANES I) -- both done by the National Center for Health Statistics. The investigators analyzed the distribution of body fat as it relates to osteoarthritis in the knees, feet, and hands.

Dr. Davis and colleagues found that the way fat was distributed on the body did not appear to be a factor in the development of osteoarthritis in the knees, hands, and feet. They found a significant association between obesity and osteoarthritis in the knees; however, they were surprised to find an even higher association between obesity and osteoarthritis in the hands and feet. The investigators note that each joint or joint group may have its own risk factors. For example, the nonweightbearing hand joints may be adversely affected by metabolic factors. In the knees, mechanical mechanisms may be involved as well. The researchers plan to continue exploring the relationship between body fat distribution and osteoarthritis and other obesity-related factors that may be causing cartilage and joint damage. This work is also supported by the NIAMS.

National Center for Research Resources

The National Center for Research Resources (NCRR) and grantees at their General Clinical Research Centers support a variety of studies focusing on arthritis.

New Treatment Looks Promising for RA

As a result of the success in using extracorporeal photochemotherapy, or ECP, to treat cutaneous T-cell lymphoma and other ailments with immunologic components, Drs. Stephen Malawista, David Troek, and Richard Edelson at NCRR's General Clinical Research Center at Yale University in New Haven, Connecticut, initiated a pilot study on seven patients with rheumatoid arthritis. ECP involves giving a patient a pill containing a light-activated drug, removing a large number of the patient's T cells, treating them with the proper wavelength of light, and then reintroducing the leukocytes back into the patient. The patient's immune system will remove these cells and actively suppress the activity of any other identical T cells that were left behind. This treatment should suppress clones of T cells that cause certain autoimmune diseases.

The researchers measured swelling and tenderness of joints and other indicators of inflammation in these patients, and found that four patients had improved -- three of them considerably -- by the fourth month of the 6-month therapy. No significant toxic side effects were found. When treatment was stopped after six months, the two patients who had improved most dramatically remained well for 2 to 3 months before they gradually became symptomatic again.

Based upon the results of this preliminary trial of ECP for rheumatoid arthritis, the investigators have begun an expanded, multi-center study comparing this new mode of treatment with a standard therapy for rheumatoid arthritis that involves injections of soluble gold salts.

Test Should Improve Steroid Treatment of Children with RA and SLE

NCRR researchers are also studying the effect of steroids on children with juvenile rheumatoid arthritis and systemic lupus erythematosus. The use of steroids produces rounded, moon-like faces; excess fat accumulation, particularly in the back of the neck and stomach areas; and various systemic problems.

To detect which children are likely to suffer the side effects of steroids, Drs. Steven Soldin and Robert Lipnick at Children's Hospital National Medical Center in Washington, D.C. adapted a steroid receptor assay for measuring steroid activity. Because a delicate balance exists between the beneficial and toxic effects of steroids, the assay will enable physicians to determine the best steroid dosages for a child more accurately.

Outlook

Clearly a new age of discovery is unfolding in the rheumatic diseases. The outlook for patients, once painfully bleak, is improving each day. In this past year, scientists have found a gene for osteoarthritis and developed an important animal model for ankylosing spondylitis. Over the past several years, researchers have identified the cause of, and developed new treatments for, Lyme disease; improved survival rates for systemic lupus erythematosus; and determined that estrogen replacement may retard the progress of osteoporosis. As new knowledge and biomedical techniques are developed, researchers will continue to make discoveries on the precise causes of and treatment for these debilitating diseases. Augmenting these Federal efforts are research programs supported by private voluntary organizations. This cooperative effort is powerful evidence of the Nation's determination to conquer all forms of arthritis, rheumatic diseases, and related disorders.

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

ARTHRITIS

The purpose of the Agency for Health Care Policy and Research (AHCPR) is to enhance the quality, appropriateness, and effectiveness of health care services and to improve access to that care. This is accomplished through the establishment of a broad base of scientific research and through the promotion of improvements in clinical practice and in the organization, financing, and delivery of health care services. The AHCPR also is responsible for facilitating the development, review, and updating of clinically relevant guidelines for specific conditions and treatments. As the focal point of Federal efforts in medical effectiveness and health services research, the AHCPR seeks to create and disseminate new knowledge and better understanding of the processes by which health services are made available and how they may be provided more efficiently and effectively.

Medical Treatment Effectiveness/Outcomes Research

Studies supported by the Agency for Health Care Policy and Research show that there are often wide variations in the types of health care furnished to apparently similar populations within and across geographic areas. Of even more concern, the research also shows that often these variations are associated with different outcomes. The Medical Treatment Effectiveness Program (MEDTEP) of AHCPR has significance for saving and extending lives, improving the quality of health care for Medicare beneficiaries and other patients, increasing and maintaining patients' functional abilities, and conserving resources. These benefits can occur as a result of new investment in the development and dissemination of scientific knowledge about patient outcomes, allowing health care providers and their patients to make more informed decisions about treatment options.

Health services research in this country and elsewhere indicates that variations in the use of health care services and procedures reflect the complex interaction of clinical, social, environmental, economic, and psychological factors that shape the relationship between patient and provider. Variations are appropriate if they arise from differences in the needs and choices of individual patients, and if the alternative patterns of care are known to be equally effective and efficient. However, the "practice styles" of physicians account for many of the differences observed in the care of patients with similar conditions, and providing physicians with information about the outcomes of care reduces these variations considerably. Practice styles are most variable for those health care conditions and procedures associated with greatest uncertainty and controversy among physicians. Research on patient outcomes and the

dissemination of its findings will help to reduce these uncertainties and resolve these controversies.

FY 1990 marked a significant expansion in the AHCPR effort to develop reliable and comprehensive data on the effectiveness of different medical treatments. Eleven Patient Outcomes Research Team (PORT) projects were funded as part of MEDTEP through the Agency's Center for Medical Effectiveness Research (CMER). These projects are multiyear and multidisciplinary studies focused on variations in clinical practice and outcomes for a particular medical condition. Each PORT project is designed to identify and analyze the outcomes and costs of alternative practice patterns for a specific condition, determine the best strategy for treatment of clinical management, and develop and test methods for reducing inappropriate variations.

Three of the eleven PORTs currently funded address alternative practice and outcomes for conditions frequently associated with severe arthritis:

Richard A. Deyo, M.D., University of Washington, Seattle, WA
"Back Pain Outcome Assessment Team" Grant No. HS 06344

Back pain is a highly prevalent and expensive condition, ranked as the second leading cause for all physician visits. The costs, both for associated health care and disability compensation are high. Geographic variations in the use of hospitalization and surgery have been well documented, and the efficacy and effectiveness of some treatments have not.

This PORT will assess alternative types of lumbar spine surgery (fusion, laminectomy, and discectomy), a variety of nonsurgical interventions (e.g., traction and various therapeutic injections), and diagnostic tests (incl. myelography, computed tomography, and magnetic resonance imaging, and thermography) commonly used for patients with back pain, especially pain due to spinal stenosis, the most common diagnosis leading to surgery among elderly patients. National and statewide hospital discharge data, Medicare claims data, and surveys of patients and physicians will be the basis for the formal decision analysis of the surgical decision that will incorporate probabilities, patient preferences for various health states, and costs. Findings will be disseminated via targeted feedback to physicians and hospitals in high use areas and by means of special materials for educating patients, whose decisionmaking role is especially important in these usually-elective procedures.

Deborah A. Freund, Ph.D., M.P.H., Indiana Univ., Indianapolis, IN
"Assessing and Improving Outcomes: Total Knee Replacements"
 Grant No. HS 06432

Progressive forms of arthritis are common, especially in the Medicare population which comprises about 70 percent of the estimated 175,000 total knee replacements performed in the U.S.

in 1990. Rates of TKR are highly variable and appear to be increasing very rapidly despite the serious lack of information about the correlates of good outcome.

This PORT will determine and explain variations in rates and outcomes of total knee replacement (TKR) for patients with a diagnosis of rheumatoid or osteoarthritis. Researchers will construct and analyze a comprehensive decision model to aid physicians and patients in deciding whether to undertake TKR, and disseminate findings to physicians and patients, with the aim of reducing the wide variation that currently exists. Analysis will focus on areas of greatest controversy, as determined by a systematic synthesis of the literature and a survey of practicing physicians, regarding the relationships between outcome and practice variables. Comparisons of outcomes will be made between TKR and non-surgical treatment for patients presenting with different degrees of pain, disability, and comorbidity. Outcomes will be assessed in terms of functional and symptomatic relief, clinical complications, costs, and associated patient utilities. The PORT will create the first comprehensive database for TKR, consisting of clinical and claims data from public (especially Medicare) and private sources for the U.S., Indiana, Western Pennsylvania, and Ontario, Canada.

James I. Hudson, M.D., University of Maryland
**"Analysis of Practices: Hip Fracture Repair and
 Osteoarthritis"**
 Grant No. HS 06658

Among Americans over 65, more than 220,000 hip fractures are recorded annually. The burden of this condition is measurable in terms of disability, dysfunction, dependence, and death. Associated annual expenditures are estimated at \$7.3 billion. Osteoarthritis (OA), which can affect the hands, feet, spine, knees, or hips, is the most common form of joint disorder and can be seen in virtually all adults by the age of 70. Total hip replacement has become a major mode of treatment for severe osteoarthritis.

This PORT will assess the effectiveness of alternative management pathways for two closely related clinical conditions, hip fracture and total hip replacement for osteoarthritis. The analysis of variations in management and outcomes will focus on immediate surgery versus delay for stabilization and alternative types of surgical repair, and on the role of rehabilitation therapy, co-morbid conditions, hospital volume for these procedures, and length of stay. Probabilities will be estimated based on a retrospective analysis of secondary data from all Medicare patients in the State of Maryland who underwent hip fracture repair or hip replacement between 1984 and 1994, and a prospective analysis of primary data for patients undergoing hip fracture or total hip replacement in the same hospitals. The primary data will come from eight Maryland hospitals that account for the highest volume of procedures under study and one-fourth

of all orthopedic surgeons in the State. The investigators will develop practice recommendations, disseminate them to physicians and the public, and measure the impact of these recommendations on practice patterns, patient outcomes, physician attitudes, and Medicare costs.

CENTERS FOR DISEASE CONTROL

National Center for Health Statistics

ARTHRITIS

Osteoarthritis and disc degeneration of the spine are major causes of disability in terms of limitation of activity and mobility among many people. Information on the prevalence of arthritis of the knee, hip, and sacroiliac joint has been published from the first National Health and Nutrition Examination Survey. Findings indicate that over 600,000 persons between the ages of 65 and 74 years have moderate to severe osteoarthritis of the knees. About 80 percent of these persons are women. In the third National Health and Nutrition Examination Survey, which began in October of 1988, information will be collected on the prevalence of osteoarthritis and rheumatoid arthritis of the hands and wrists and of the knees for persons 60 and above. This information will be used to update national prevalence estimates and to provide a baseline population for follow-up studies.

The National Health Interview Survey for 1986-1988 estimated the number of conditions of known arthritis in the civilian, noninstitutionalized population of the United States was 31,233,000 or 130.9 conditions per 1,000 persons. Of these conditions, 19.8 percent caused limitation of activity, 8.7 percent caused one or more hospitalizations in the past year, and 81.7 percent resulted in one or more physician visits in the past year. In 1989, the estimated number of known arthritis conditions was 30,999,000 or 127.3 per 1,000 persons per year.

According to the 1989 National Hospital Discharge Survey, an estimated 383,000 patients were hospitalized in short-stay hospitals in the United States with a first-listed diagnosis of arthritis. Their average length of stay was about 7.8 days. Almost 55 percent of these patients were women and 69 percent of the patients were 45 years and older. About 55 percent of the 383,000 patients had a specific diagnosis of osteoarthritis and allied conditions. There were an additional 947,000 diagnoses of arthritis that were not first-listed. Although some of these were additional diagnoses for the patients with a first-listed arthritis diagnosis, the majority of these 947,000 diagnoses were secondary to other diagnoses.

In addition to the figures above, patients with a first-listed diagnosis of spinal arthritis (ankylosing spondylitis and spondylosis and allied disorders) totaled 59,000 discharges in 1989. There were an additional 165,000 secondary diagnoses of spinal arthritis in 1989.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

CHILD CARE

CHILD CARE

Appropriations
(in millions)

	1988 Actual	1989 Actual	1990 Estimate	1991 Estimate	1992 Estimate
Family Support					
Administration (Total).....	--	\$17.0	\$135.0	\$1,211.9	\$1,478.3
* JOBS-Related and Transitional Child Care	--	17.0	122.0	317.0	433.0
* Non-AFDC (At-Risk) Child Care	--	--	--	150.0	300.0
* Child Licensing Improvement Grants	--	--	13.0	13.0	13.0 1/
* Child Care and Development Block Grants	--	--	--	731.9	731.9 1/
* Community Services Block Grants 2/	n/a	n/a	n/a	n/a	n/a
* Research and Demonstration	--	--	--	--	0.4
Office of Human Development Services (Total).....	\$676.2	\$679.1	\$670.7	\$686.5	\$685.7
.. Social Services Block Grant (Title XX) 3/	660.0	660.0	660.0	660.0	660.0
* Child Welfare Services 4/	n/a	n/a	n/a	n/a	n/a
* Dependent Care Planning and Development	8.3	11.9	13.2	13.2	13.2
* Child Development Associate Scholarship	1.4	1.5	1.4	1.4	1.4
* Temporary Child Care Crisis Nurseries.....	4.8	4.9	8.3	11.1	11.1
* Research and Demonstration	1.7	0.8	0.8	0.8	--
* Head Start 5/	[1,206.3][1,235.0][1,552.0][1,952.0][2,052.0]				
Public Health Service					
Research and Demonstration.....	\$3.4	\$6.9	\$7.3	\$8.3	\$8.4
Assistant Secretary for Planning and Evaluation -					
Research and Evaluation.....	\$0.7	\$0.6	\$0.6	\$0.3	\$0.4
ALLS TOTAL.....	\$680.3	\$703.6	\$813.6	\$1,907.0	\$2,172.8

(CHILD CARE TABLE FOOTNOTES)

- 1/ Funding for this activity in FY 1992 is included in the "Payments to States for Child Care Assistance" appropriation request.
- 2/ The Community Services Block Grant provides grants to States to go to local community action agencies for local antipoverty activities, which may include child care. No data on such expenditures is provided to the Federal government.
- 3/ Estimates based upon HHS-sponsored research have been used for the cost of day care services which States may choose to provide under the Social Security Act's Title XX formula grants program.
- 4/ Title IV-B of the Social Security Act establishes matching grants to States who may provide child care and assist child care centers in meeting licensing requirements, but no cost estimates are available.
- 5/ Data for the Head Start program are listed for information but have not been included in totals for the Office of Human Development Services because Head Start is a comprehensive child development program rather than a child care program.

FAMILY SUPPORT ADMINISTRATION

o JOBS and Transitional Child Care

Under the provisions of the Family Support Act of 1988, all States are required to guarantee child care services to eligible AFDC recipients if such services are necessary for employment. Child care must also be guaranteed to AFDC recipients who are participating satisfactorily in State-approved education or training activities including JOBS. All States were operating a JOBS program as of October 1, 1990. In addition, as of April 1990 all States are providing 12 months of transitional child care to former AFDC recipients who have left the AFDC rolls as a result of increased earnings or higher income.

o Non-AFDC (At-Risk Child Care)

The Omnibus Budget Reconciliation Act of 1990 authorized \$300 million annually for allocation to States beginning in FY 1991 to provide child care to low-income families who (1) are not receiving AFDC benefits, (2) need such care in order to work, and (3) would otherwise be at risk of becoming eligible for AFDC. Families must contribute to the cost of providing the care according to a sliding fee scale formula based on the family's ability to pay.

o Child Care Licensing Improvement Grants

The Family Support Act of 1988 provided \$13 million in FY 1990 and \$13 million in FY 1991 for grants to States for the improvement of licensing and registration requirements and for monitoring the quality of child care being provided to AFDC children under approved State plans. The Omnibus Budget Reconciliation Act of 1990 extended and changed the purpose of the grant program to include the training of child care providers and the enforcement of child care standards. The FY 1992 budget includes the same level of funding for this program as in FY 1991 in the Payments to States for Child Care Assistance account which includes funding for the Child Care and Development Block Grant.

o Child Care and Development Block Grant

The Child Care and Development Block Grant Act of 1990 provides grants to States for the purpose of providing low-income families with financial assistance for child care, for improving the quality and availability of child care, and for establishing or expanding early childhood development programs. Funds for this program are allotted to each State based upon a formula that includes the relative per capita income of each State, each State's share of the total national number of children under five, and the percentage of children receiving free or reduced price school lunches in each State.

o Research and Demonstration

Research studies will be undertaken to examine the effects of transitional child care services on welfare dependency. In addition, demonstration grants and research contracts will focus on specific issues dealing with the efficiency and effectiveness of child care delivery systems.

OFFICE OF HUMAN DEVELOPMENT SERVICES

Child Care ActivitiesSocial Services Block Grant

- o In fiscal year 1990, forty-five States reported that they provided day care services under the Social Services Block Grant (title XX of the Social Security Act), a \$2.8 billion formula grant program. Child care services must comply with applicable State and local law. Estimates of State expenditures of title XX funds for day care totaling \$660 million are based upon HHS-sponsored research.

Child Welfare Services

- o Title IV-B of the Social Security Act establishes 75 percent matching grants to the States. States may provide child care and may also assist child care centers in meeting State and local licensing requirements. No capital costs for child care facilities may be paid and each State's spending for child care services necessary solely for employment or training is limited to that available in fiscal year 1979. There is no State reporting on the portion of IV-B funds which are expended related to child care.

Dependent Care Planning and Development

- o The Dependent Care Planning and Development program was authorized in 1984. Grants to States pay 75 percent of the planning and development costs to establish information and referral systems and school-age day care. Grants may not be used for operating or capital costs, nor for direct payments or services to beneficiaries.

Child Development Associate Scholarship Program

- o The Child Development Associate Scholarship Program began in 1987. States and areas receiving grants under the Social Services Block Grant are eligible to apply for grants, which are distributed in the form of scholarships to income eligible candidates for the child development associate credential.

Other Research

- o Under an HDS partnership with the National Academy of Sciences, a multi-disciplinary Panel on Child Care Policy examined the state-of-the-art on child care and recommended child care options along with their associated costs. Additionally, the National Association for the Education of Young Children is conducting a National Child Care Study which will be completed in 1991.

Temporary Child Care and Crisis Nurseries

- o The Temporary Child Care for Children with Disabilities and Crisis Nurseries program provides demonstration grants to States to assist private and public agencies and organizations to provide (1) in-home or out-of-home temporary non-medical child care for children with disabilities and children with chronic or terminal illnesses and (2) crisis nurseries for children who are abused and neglected, are at high risk of abuse and neglect, or who are in families receiving child protective services.

Public Health Service
Child Care Research and Demonstration

- o Last year, the National Institute of Child Health and Human Development reported on the NICHD Study of Early Child Lives (formerly called the "National Study of Young Children's Lives"). This study focuses on the impact of care environments on child development. It has been funded as a cooperative agreement and is composed of 10 research sites. The 10 research sites are at the University of Arkansas, University of California-Irvine, University of Kansas, University of Pittsburgh, University of New Hampshire, Temple University, University of Virginia, University of Washington, University of Wisconsin and Western Carolina Center. These different sites provide geographical diversity and, consequently, the potential for a heterogeneous subject pool. The study is being developed by a steering committee consisting of the principal investigators of the study, NICHD staff, and an independent chairperson. The committee is assisted by a statistical consultant. Data management, monitoring and analysis will be carried out centrally by NICHD. Total funding for FY 1991 will be carried out centrally by NICHD. Total funding for FY 1991 is estimated at \$4.1 million. The estimate for FY 1992 is also \$4.1 million.
- o Since the study has just started to enroll subjects, no data has been collected to date. The collection protocol is being developed and the final protocol should be completed between October and December of 1991. Enrollment into the study will take place at birth and will be ongoing up to ten months. This activity started in January and will be completed in October, 1991. During the period of enrollment, it will take the full ten months to get the entire sample of 1,200 families; however, during the enrollment period, the one month and six month data points will be collected on some of the children. There will be additional data collection points at 15 month, two year, and three years. There will be several telephone contacts between each regularly designated data collection point of time. There will be a different protocol for each data collection point.
- o The Maternal and Child Health Bureau continues to fund projects addressing health and safety in child care settings. There are currently 14 funded projects within MCHB addressing child health status improvement, and the development of child care health systems networks. A current project being conducted through the American Public Health Association (APHA) and American Academy of Pediatrics is the development of National Health and Safety Performance Standards in Out-of-Home Child Care Programs. The goal of the project is to

develop guidelines for health and safety that could support parents, health care providers, early childhood educators, and policymakers in their efforts to protect and maintain the health and safety of children enrolled in out-of-home child care programs. The development of these guidelines will draw upon the expertise of a diverse group of professionals with backgrounds in medicine, nursing, social work, health education, nutrition, sanitation, psychology, early childhood education, law and other related fields. The final report on this project is scheduled to be published by the APHA/AAP in June 1991.

ASSISTANT SECRETARY FOR PLANNING AND EVALUATION

Child Care Research and Evaluation

The Family Support Act of 1988 instituted a Job Opportunities and Basic Skills (JOBS) program which requires AFDC recipients to engage in education, employment, or job training as a condition for receiving AFDC benefits.

The Assistant Secretary for Planning and Evaluation (ASPE) has responsibility for evaluating the JOBS program. Part of this evaluation will examine the effects of parents' participation in JOBS on their children's development. The evaluation contractor, MDRC, has subcontracted with ChildTrends Inc. to produce research design options outlining the effect of participation, controlling for family variable and alternative care arrangements, on children's social, emotional, cognitive, and physical development.

ASPE also plans to help fund an intensive longitudinal study of the effect of alternative care arrangements and family environment on infants' development. National Institute of Child Health and Human Development's Infant Care Network is following 1,200 families with infants in ten sites for three years, documenting infants' developmental milestones, and will assess the effects of child care variables and family functioning variables on the outcomes.

CYSTIC FIBROSIS
Obligations

	<u>1988</u> <u>Actual</u>	<u>1989</u> <u>Actual</u>	<u>1990</u> <u>Actual</u>	<u>1991</u> <u>Estimate</u>	<u>1992</u> <u>Estimate</u>
<u>National Institutes</u> <u>of Health:</u>					
National Institute of Diabetes and Digestive and Kidney Diseases...	\$9,924,000	\$10,375,000	\$10,867,000	\$12,600,000	\$13,500,000
National Cancer Institute.....	11,000	---	190,000	203,000	210,000
National Heart, Lung and Blood Institute.....	6,933,000	6,940,000	9,675,000	10,181,000	10,950,000
National Institute of Dental Research.....	7,331,000	7,588,000	9,317,000	10,271,000	11,186,000
National Institute of Allergy and Infectious Diseases.....	7,910,000	9,804,000	7,254,000	7,849,000	8,562,000
National Institute of General Medical Sciences.	50,000	50,000	50,000	50,000	50,000
National Institute of Child Health and Human Development.....	93,000	109,000	385,000	400,000	450,000
National Eye Institute.....	---	---	282,000	298,000	313,000
National Institute of Environmental Health Sciences...	121,000	112,000	---	---	---
National Institute of Arthritis and Musculoskeletal and Skin Diseases.	162,000	162,000	192,000	222,000	237,000
National Center for Research Resources.....	870,000	907,000	850,000	842,000	774,000
Total, NIH.....	33,405,000	36,047,000	39,062,000	42,916,000	46,232,000

NATIONAL INSTITUTES OF HEALTH

National Institute of Diabetes and Digestive
and Kidney DiseasesCYSTIC FIBROSIS

In 1991, cystic fibrosis (CF) remains the most common fatal genetic disease of Caucasians in the United States. Although there is still no cure, the discovery of the CF gene in August, 1989 has energized researchers, who are collaborating in increasing numbers to improve treatment and to heal the 30,000 American children and young adults in the U.S. who suffer from this lethal disease.

Each year, 1,000 new cases of CF are diagnosed, approximately one in every 2,000 births. Children with CF suffer from chronic lung and digestive problems caused by the build-up of thick, sticky mucus that marks the disease. Males with the disease are usually sterile. Although the life expectancy of children with CF has increased steadily, most die of respiratory failure before age 30.

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) conducts and supports studies on the genetics, physiology, and therapy of CF. Although NIDDK leads and coordinates CF research at the National Institutes of Health (NIH), the National Heart, Lung and Blood Institute (NHLBI), the National Institute of Dental Research (NIDR), and the National Institute of Allergy and Infectious Diseases (NIAID) also support a significant amount of research on this disorder. In addition, the National Institute of General Medical Sciences (NIGMS), the National Institute of Child Health and Human Development (NICHD), the National Institute of Environmental Health Sciences (NIEHS), the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and the National Center for Research Resources (NCRR) support CF research. The National Center for Human Genome Research (NCHGR) is also supporting research on the development of maps--which show the location of certain identifiable landmarks--of human chromosomes. These should aid scientists in their search for genetic causes of CF and other diseases.

CF Causes Chronic Lung and Digestive Disease

CF is a disease of the exocrine glands, glands with ducts that channel secretions such as saliva, sweat, and mucus to different parts of the body. In CF, these secretions are too thick. Sweat is abnormally salty. Mucus is so thick that it interferes with the digestive enzymes in the pancreas, often

causing malnutrition; it also clogs the lungs, making breathing difficult and causing chronic cough and infection.

Presently, treatment is limited to enzyme supplements to aid digestion; medicated inhalants; antibiotics to help control the bacterial infections that rise so easily in the mucus-clogged lungs; and chest physical therapy that includes "postural drainage" (vigorous, rhythmic clapping of the patient's chest and back to loosen mucus so that it can be expelled from the lungs). The severity of CF varies from person to person, but for many, CF means frequent and lengthy hospitalizations; the physical, emotional, and financial strain of living with a chronic disease; and the anguish of anticipating a premature death.

Basic Cell Biology and Molecular Technology Set Stage for Discovery

Without the basic research strides in cell biology and recombinant DNA technology accomplished in the 1970's and the 1980's, researchers could not have discovered the CF gene. Improved techniques for culturing and studying cells led to the knowledge that the sweat gland ducts of CF patients do not allow normal chloride transport. This insight into the disease, along with molecular advances such as the ability to copy strands of DNA, to cut them with enzymes, and to analyze and compare them enabled scientists to identify the gene and make subsequent progress toward understanding and correcting the defect.

The discovery of the CF gene has opened a bottleneck in CF research, making it possible to analyze how defects in this gene cause the disease. The discovery has also focused attention on identification of multiple mutations of the gene; the potential use of gene therapy to cure the disease; and experiments to understand the function of the protein produced by the CF gene, knowledge that could result in effective medical treatment.

CF is a Genetic Disorder

CF is an autosomal recessive trait, meaning that a child will develop the disease only if he or she inherits two mutant CF genes, one from each parent. When both parents are carriers of the CF gene, the child has a one-in-four chance of having CF. A child who inherits only one abnormal gene becomes a carrier and can transmit the disease but will not have symptoms of the disease.

The gene identified last year by NIDDK-supported researchers Drs. Lap-Chee Tsui and Jack Riordan of the Hospital for Sick Children in Toronto, Ontario, and Dr. Francis Collins of the University of Michigan in Ann Arbor is a code for the cystic fibrosis transmembrane regulator (CFTR)

protein. Researchers believe that CFTR regulates ion transport across cell membranes, and when defective, contributes to the imbalance of sodium and chloride in the abnormal secretions characteristic of CF. Researchers found that in a majority of patients with CF, three of the gene's thousands of building blocks are missing, so that one amino acid among the 1,480 that make up the CFTR protein is absent. This mutation, called Delta F508, occurs in 70 percent of those who have CF.

CF Gene Replaced with Normal One in Cell Cultures

One year later, the same NIDDK-supported research teams who discovered the gene and another supported by NHLBI--led by Dr. Michael Welsh at the University of Iowa in Iowa City--have accomplished a second breakthrough, replacing the defective gene with a normal one in cells growing in culture. A defective gene produces a flawed protein that impairs regulation of chloride channels, resulting in dehydration and other changes in the composition of the protective mucus layer outside the cell. The resulting thick mucus becomes a breeding ground for bacteria. Dr. Francis Collins of the University of Michigan and Dr. Raymond Frizzel of the University of Alabama in Birmingham used a retrovirus (a virus composed of RNA--ribonucleic acid--rather than DNA--deoxyribonucleic acid) to insert a normal gene into the chromosome of a pancreatic cell taken from a CF patient. When the normal gene began producing its protein, CFTR, it normalized the function of the chloride channel that is impaired in CF.

This latest stride has raised hopes that CF may someday be treated with gene therapy. Scientists believe that an aerosol might be devised to deliver the normal gene via genetically engineered viruses--or even the protein itself--to the patient's lungs. Because lung cells are constantly being replaced, however, such an aerosol might need to be administered frequently. Researchers do not yet know the location of the "stem cells" that generate the cells lining the lung's airways. If these cells can be identified and normal genes inserted in them, the corrected stem cells may reproduce healthy cells on a regular basis.

Genetic Characteristics Define Clinical Profile of CF

CF varies in its symptoms and severity; one patient may have severe pancreatic problems while another suffers more from lung infections. In the first major attempt to understand these differences by analyzing specific genetic mutations such as Delta F508, Dr. Lap-Chee Tsui and colleagues at the Hospital for Sick Children examined blood samples of 293 CF patients from 233 families. They found that certain clinical characteristics may arise from specific genotypes of the disease. About 99 percent of the patients with two copies

of Delta F508 suffered from pancreatic insufficiency and tended to have more severe forms of the disease: they were diagnosed at younger ages, had worse pulmonary disease and weighed less for their age. By contrast, CF patients with a different genotype, such as one copy of Delta F508 and a copy of another mutation, tended to have milder forms of the disease.

Genetic Tests Are Useful Adjuncts in Diagnosis of CF

Former NIDDK researcher Dr. Paul di Sant' Agnese used the abnormal levels of salt in the sweat of CF patients to develop the sweat test, which has been the diagnostic standard since 1953. However, the test was difficult to perform and interpret, particularly in newborns. It may be difficult to obtain enough sweat from them for a viable test, and their sweat electrolyte levels are elevated during the first days of life. Genetic tests now provide a useful adjunct to confirm a diagnosis of CF in both newborns and older children suspected of having the disease.

Widespread Screening for the CF Gene Not Advised

Researchers who identified the primary CF mutation, Delta F508, had hoped to quickly identify a small number of additional mutations causing CF and then devise a screening test to identify the one in every 20 Americans who unknowingly carries the gene. However, Delta F508 accounts for only approximately 70 percent of carriers. The remainder have one of a wide variety of rare, sometimes unique, mutations. Because there are a sizable number of mutations that account for the remaining 30 percent of carriers, simple screening tests cannot identify those individuals who would still be at increased risk for bearing a child with CF. A workshop was organized last March by NIDDK, and co-sponsored by NHLBI, NICHD, NCHGR, the National Center for Nursing Research, and the Office of Medical Applications of Research.

Chaired by Drs. Arthur Beaudet of Baylor College of Medicine in Houston, Texas, and Haig Kazazian of Johns Hopkins University School of Medicine in Baltimore, Maryland, the group advised that carrier testing should be offered to all people with a family history of CF, but that widespread screening of the general population is not advisable until screening tests achieve 95-percent detection rates. The scientists concluded that screening should be voluntary and confidential, and should be given only with informed consent; education and counseling should accompany testing; and quality control and equal access are important issues. The workshop members also called for pilot programs to evaluate issues such as cost and the medical and psychosocial aspects of widespread screening.

To date, however, the search for the additional mutations

that would allow 95-percent carrier detection has been frustrating. Eighty collaborating laboratories have so far identified another 60 mutations, many of which have been found in just one person.

Knowledge of Chloride Channel Activity May Offer Alternative Therapies

In addition to exploring the potential for gene therapy, scientists are studying ways to correct the defective regulation of chloride channels in CF patients. Intramural scientists Dr. Z. I. Cabantchik and colleagues have studied how various chemical activators affect chloride movement in HT-29, T-84 and CF-PAC cells (HT-29 and T-84 are lines of human cells that are used for studying chloride ion transport properties. CF-PAC are lines derived from pancreatic cells of CF patients). They found enormous variation in the way cells respond and concluded that in HT-29 and CF-PAC cells chloride channels could be activated through multiple pathways. This raises the prospect of devising other possible therapies to control dysfunctional chloride secretion in CF. The scientists are trying to determine the specific molecular pathways involved in regulation of the chloride channel. They hope to isolate and purify each component of the channel and the elements regulating it. Such a system would provide a way to test drugs and other agents that might normalize chloride channel function.

National Heart, Lung and Blood Institute

Research on CF supported by the National Heart, Lung and Blood Institute (NHLBI) focuses on the pulmonary complications of CF, which are the major cause of morbidity and mortality in CF.

Progress Toward Gene Therapy is Reported

In an effort to develop possible genetic approaches to controlling this disease, NHLBI intramural scientists led by Dr. Ronald Crystal have quantified the level of expression of the CF gene in normal persons and in patients with CF, have characterized the controlling elements of expression of the normal gene, and have developed a strategy for transferring normal genes directly into the cell lining of the respiratory tract. This strategy seeks to employ common respiratory system viruses as the vehicles to carry the normal CF genes into the hard-to-reach airways cell linings. Years of work lie ahead to assure that the genes are transferred effectively, adequately and safely.

Compounds Found to Help Treat CF Patients

Alpha 1-antitrypsin is a blood protein that normally protects the lung tissue from destruction by another protein, elastase. Dr. Crystal has shown that use of aerosol alpha 1-antitrypsin to increase its levels in the epithelium (surface cells) of the respiratory tract of CF patients can reduce to undetectable levels the proteolytic (digestion of proteins) activity that is a major source of lung damage in CF patients.

NHLBI grantee Dr. Michael Knowles and collaborators at the University of North Carolina at Chapel Hill have found that the drug amiloride may have a therapeutic role in the treatment of CF lung disease. Preliminary results from a pilot study of amiloride aerosol in 14 adults with CF indicate that the compound can slow the disease-induced decline in lung function and thin airway secretions, thereby facilitating clearance of mucus from the airways.

National Institute of Dental Research

The National Institute of Dental Research (NIDR) conducts and supports research relevant to cystic fibrosis primarily through studies of saliva and salivary gland secretions. By studying normal salivary processes, NIDR scientist hope to determine what goes awry in the secretory mechanisms of CF patients.

Advances Are Made in Understanding Salivary Gland Secretion

NIDR intramural scientists have continued their efforts to understand the mechanisms that control secretion by the salivary and other exocrine glands. Previous research has shown that elevated levels of calcium in salivary cells play a central role in permitting prolonged fluid secretion. The initial increase in calcium levels is triggered by its release from an intracellular storage pool. For sustained fluid secretion to occur, however, calcium must enter the cell from the extracellular fluid. The mechanism by which calcium does this has been unclear.

During the past year, NIDR intramural scientists Drs. Lawrence Mertz, Bruce Baum, and Indu Ambudkar characterized the neurotransmitter-stimulated pathway by which calcium enters one of the major salivary glands in the rat. They found that stimulation of this pathway is mediated by the activation of G proteins--an information transfer system in the cell; is calcium dependent on extracellular concentration; is modulated by the calcium content of the intracellular storage pool; and allows calcium to enter directly into the cell's cytoplasm. Importantly, the levels of calcium found in the cell, even following prolonged stimulation, are capable of supporting substantial continued chloride secretion from the cells and, therefore, adequate fluid secretion.

NIDR intramural scientists Drs. James Turner and Michel Manganel have shown that the elevated calcium levels occurring in salivary cells during secretion also play a role in regulating other cellular events. They have demonstrated that calcium levels can modulate pH (degree of acidity or alkalinity) in the rat salivary cell by regulating the activity of a major membrane transport protein, the sodium/proton exchanger. During secretion, salivary gland cells would become very acidic and thus suffer a reduction in function were it not for the activation of the sodium/proton exchanger and its subsequent buffering of the acidity.

Insight Gained into Lung Complications of CF

Antibiotic-resistant bacteria breed in the thick, abnormal mucus that obstructs breathing pathways in CF patients. NIDR intramural scientists Drs. Sharon Wahl, Phillip Smith, and Uwe Mai suggest that the chronic presence of harmful bacteria in

the airways of CF patients may stimulate a continuous immune response, the by-products of which promote inflammation and fibrosis (formation of fibrous tissue).

The investigators compared lung macrophages (white blood cells residing in the lung that are essential to healing and protecting the body from viruses and bacteria) from CF patients with those from healthy persons. They found that the lung macrophages in CF patients produce significantly higher than normal amounts of cytokines, strong mediators of inflammation that also stimulate special cells to trigger the process of fibrosis. This finding points to a possible mechanism for the pulmonary fibrosis in CF patients and suggests that therapies aimed at controlling the activity of these cytokines could alleviate the respiratory complications of this disease.

National Institute of Allergy and Infectious Diseases

The National Institute of Allergy and Infectious Diseases (NIAID) supports research on the mechanisms by which infectious organisms cause disease and uses this knowledge to develop improved therapies to treat diseases and to develop vaccines to prevent them.

Mortality and morbidity among CF patients are most commonly attributed to the bacterium Pseudomonas aeruginosa, which causes chronic pulmonary infection. Currently there is no treatment for patients with P. aeruginosa, which infects 87 percent of CF patients by their 15th birthday.

Researchers Immunize Rodents to Protect Against Infection

At the Brigham and Women's Hospital in Boston, Massachusetts, NIAID grantee Dr. Gerald B. Pier and his colleagues immunized rodents against infection by P. aeruginosa. Prior research has shown that a particular immune system protein known as an opsonizing antibody (an antibody that makes bacteria susceptible to ingestion by white blood cells) may provide protection against P. aeruginosa. This antibody is specific for the mucoid exopolysaccharide (MEP), a mucus-like substance surrounding P. aeruginosa bacteria, and may provide protection. Nonopsonizing antibodies to MEP do not protect against infection and these antibodies are the ones that CF patients make when they are infected.

Although no animal model for CF exists, Dr. Pier and his colleagues induced chronic lung infection in mice and rats by injecting P. aeruginosa enmeshed in agar beads--a gelatinous substance in which bacteria grow. The rodents had already been immunized with MEP that, in small doses, elicited opsonizing antibodies or, in large doses, elicited nonopsonizing antibodies. Rodents immunized with doses of MEP that elicited opsonizing antibodies had less severe lung infection than those immunized with doses of MEP that elicited nonopsonizing antibodies.

Using MEP as a vaccine in CF patients will be difficult for various reasons. For example, it is possible that the immune system of CF patients may be unable to produce opsonizing antibody to MEP. The biological barriers would have to be overcome before vaccine trials in CF patients with cystic fibrosis could be undertaken.

Outlook

The discovery of the CF gene one year ago, followed by successful in vitro gene transfer experiments by two different teams, have electrified the CF research community. Investigators are using the CF gene to develop an animal model for CF to learn more about the disease and what alleviates it. They are working to determine the function of the gene's product, the CFTR protein, and its role in causing the disease. Other scientists are studying new drugs that will break down the thick mucus produced by CF. Scientists are increasingly optimistic about the prospect for major therapeutic advances and perhaps even a cure for CF.

DIABETES AND RELATED RESEARCH
Obligations

	<u>1988</u> <u>Actual</u>	<u>1989</u> <u>Actual</u>	<u>1990</u> <u>Actual</u>	<u>1991</u> <u>Estimate</u>	<u>1992</u> <u>Estimate</u>
<u>National Institutes</u> <u>of Health:</u>					
National Institute of Diabetes and Digestive and Kidney Diseases..	\$146,988,000	\$160,532,000	\$163,276,000	\$170,300,000	\$180,500,000
National Cancer Institute.....	819,000	929,000	1,041,000	1,104,000	1,152,000
National Heart, Lung and Blood Institute.....	15,109,000	16,101,000	15,672,000	16,500,000	17,700,000
National Institute of Dental Research.....	3,010,000	4,318,000	1,819,000	1,975,000	2,157,000
National Institute of Neurological Disorders and Stroke.....	7,995,000	9,383,000	5,641,000	5,924,000	6,338,000
National Institute of Allergy and Infectious Diseases.....	6,553,000	5,336,000	5,633,000	6,090,000	6,652,000
National Institute of General Medical Sciences.	2,585,000	2,668,000	2,261,000	2,400,000	2,600,000
National Institute of Child Health and Human Development.....	12,168,000	13,343,000	12,921,000	14,000,000	15,200,000
National Eye Institute.....	22,050,000	21,086,000	17,103,000	17,787,000	18,499,000
National Institute of Environmental Health Sciences..	178,000	196,000	257,000	268,000	279,000
National Institute on Aging.....	4,772,000	4,805,000	5,010,000	5,260,000	5,523,000
National Center for Research Resources 1/.....	16,771,000	17,432,000	17,052,000	17,388,000	17,516,000
National Center for Nursing Research.	1,515,000	1,324,000	212,000	250,000	300,000
Office of the Director 2/.....	369,000	753,000	93,000	100,000	190,000
Total, NIH....	240,882,000	258,206,000	247,991,000	259,346,000	274,606,000

DIABETES AND RELATED RESEARCH - continued
Obligations

	<u>1988</u> <u>Actual</u>	<u>1989</u> <u>Actual</u>	<u>1990</u> <u>Actual</u>	<u>1991</u> <u>Estimate</u>	<u>1992</u> <u>Estimate</u>
<u>Centers for</u> <u>Disease Control.....</u>	10,100,000	10,100,000	10,100,000	10,100,000	10,120,000
<u>Alcohol, Drug Abuse,</u> <u>and Mental Health</u> <u>Administration.....</u>	300,000	613,000	1,143,000	1,310,000	1,386,000
<u>Agency for Health</u> <u>Care Policy and</u> <u>Research.....</u>	---	---	1,866,000	2,372,000	2,372,000
<u>Indian Health</u> <u>Service.....</u>	2,900,000	3,900,000	5,333,000	6,300,000	6,671,000
Total, PHS....	254,182,000	272,819,000	266,433,000	279,428,000	295,155,000

1/ This includes RCMI awards. Prior to FY 89, RCMI's were shown in OD.

2/ This includes AREA awards for FY 1988 - 1992, and RCMI awards for 1988.

NATIONAL INSTITUTES OF HEALTH

National Institute of Diabetes and
Digestive and Kidney DiseasesDIABETES

One of the most common chronic diseases in America today, diabetes mellitus now affects an estimated 12 million Americans, half of whom don't know they have it. Every year 500,000 people develop the disease, which disproportionately affects several of the nation's minority groups--including Blacks, Hispanics, American Indians, and native Hawaiians. Diabetes costs the country \$20.4 billion a year in medical care and lost productivity.

Even with good care, many patients with long-term diabetes eventually suffer devastating consequences. They are twice as likely to have a stroke or heart disease and 15 times more likely to suffer a non-accident related amputation than those without the disease. Diabetes is the leading cause of new cases of blindness in the United States, causing 6,000 people a year to lose their sight. It is also the single largest cause of kidney failure in this country, accounting for 30 percent of all new cases of end-stage renal disease. The federal government pays for 90 percent of the treatment for end-stage renal disease, a bill that came to \$4.4 billion in 1987. Finally, diabetes is the fifth leading cause of disease-related deaths in this country.

Diabetes Saps Energy and Damages Organs

Diabetes occurs when the body is not able to metabolize glucose (sugar) properly. Normal digestion of food produces glucose, which enters the bloodstream. With the help of insulin, a hormone released by the islet cells of the pancreas, glucose is converted into energy. But when a person has diabetes, the body does not make or use insulin properly. The body is then deprived of its primary fuel, and an excess of glucose accumulates in the blood. Over time, uncontrolled high glucose levels can damage the heart, the kidney, the eyes, and the nerves, and can cause coma and death.

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and several other institutes at NIH, including the National Institute of Environmental Health Sciences and the Office of the Director, support research to discover the causes of diabetes as well as methods to prevent it and its complications. Among the advances NIDDK grantees have reported this year is the identification of a protein said to be the earliest and best predictor of insulin-

dependent diabetes (IDDM), in which the islet cells fail to produce insulin. Researchers have also gained further knowledge about other "markers" that may lead to development of a simple screening test for IDDM, and have made new strides in islet cell transplantation. Scientists studying non-insulin-dependent diabetes (NIDDM) have begun a search for the genes they suspect determine susceptibility to the disease, in which either the islet cells do not produce enough insulin or a normal amount is produced but the body's tissues do not respond to it, or both. They also have found that insulin resistance, which makes a person susceptible to NIDDM, appears to have a genetic basis.

Insulin-dependent Diabetes Is an Autoimmune Disease with Contributing Genetic Factors

IDDM, which usually occurs in children and young adults, affects almost one million Americans. Without daily insulin injections, a person with this form of diabetes will die. Scientists now know that IDDM is an autoimmune disease that occurs when the body's immune system begins to target and destroy its own healthy islet cells so that the body cannot produce insulin. By the time diabetes becomes evident, nearly all of these insulin-producing islet cells have been destroyed.

Scientists now believe that certain genes contribute to a person's vulnerability to autoimmune attack, but nobody knows why the immune system turns against the body's own tissue, leading to diabetes. Investigators continue to study which parts of the immune system are the primary attackers, what triggers the autoimmune attack, and what allows it to continue.

For some time, investigators have been focusing on a link between diabetes and protein found in islet cells called 64K. Several studies have shown that 70 to 80 percent of newly diagnosed and prediabetic persons have high levels of antibodies to the 64K protein. These antibodies can be found in the blood of prediabetics up to 8 years before symptoms appear. NIDDK-supported researchers Drs. Mark Atkinson, William Riley and Noel Maclaren of the University of South Florida at Gainesville and David Scharp, and Paul Lacy at Washington University in St. Louis, Missouri suggested that, based on their recent studies, 64K antibodies may be the earliest and best indicator of impending insulin-dependent diabetes. However, some people with high levels of these antibodies don't develop IDDM. For this reason, some researchers believe that 64K helps to initiate IDDM but requires some immune system trigger not yet identified.

Chemical Composition of 64K Antigen Is Determined

In September, NIDDK grantees Drs. Steinunn Baekkeskov of

the University of California, San Francisco, and Pietro DiCamilli of Yale University in New Haven, Connecticut, and their colleagues showed that the 64K protein is an enzyme, glutamic acid decarboxylase (GAD), found in high concentrations in islet cells. Identifying a protein that signals the body's misguided attack on its own cells is a key element in devising a simple blood test that can be used to screen large populations for early detection of IDDM, and ultimately, developing methods to prevent the disease. GAD also is found in the brain in levels high enough to encourage further research on this important protein.

Other Markers Provide Clues to IDDM

The first precise genetic link with IDDM was found in the HLA-DQ beta genes. These genes control the production of proteins that are attached to the surface of certain cells and help the immune system's T cells recognize foreign matter and trigger an immune response to rid the body of it. Researchers have found that people who have the amino acid aspartic acid at position 57 (Asp 57) of the protein coded for by the HLA-DQ beta gene did not develop IDDM, while those with another amino acid at that position (non-Asp 57) were at risk for the disease. The Asp 57 marker seems to be an accurate indicator of low risk for IDDM, except among some minority groups. NIDDK investigators are studying these markers to determine how well they predict susceptibility to IDDM.

This year, work supported by NIDDK and NIAID on HLA-DQ beta genes has suggested that the genetic profile of IDDM is complex and multifaceted, and that one needs to do complete HLA-DQ typing to assess a person's susceptibility to the disease. Details on this research by Dr. J. Donald Capra at the University of Texas Southwestern Medical Center in Dallas are given in the NIAID section of this report.

The incidence of IDDM varies widely among countries and racial groups, and has led scientists to speculate that nutrition, climate, and other environmental factors might be the reason. In related NIDDK-supported research, Dr. Janice Dorman and colleagues at the University of Pittsburgh examined the prevalence of the HLA-DQ Asp 57 marker in five different ethnic groups. They also found that the presence of the Asp 57 marker indicates low risk for IDDM. This suggests a genetic explanation for the wide variation in the incidence of IDDM among various ethnic groups.

Screening Sets the Stage for Preventive Therapy

NIDDK grantee Dr. George S. Eisenbarth of the Joslin Diabetes Center in Boston has been studying genetic markers that predict with high probability the onset of IDDM. He tested close relatives of IDDM patients and found that when they had islet cell antibodies, insulin autoantibodies, and an

immediate reduction in the amount of insulin released after intravenous glucose, they almost always develop IDDM in less than 10 years. With this knowledge, NIDDK grantees Drs. Noel Maclaren, Kevin Lafferty of the University of Colorado at Denver, and Ake Lernmark of the University of Washington, Seattle, along with Dr. Eisenbarth, are screening persons whose relatives have IDDM to identify those who appear to be at very high risk for the disease in the near future. This prediabetic population will participate in clinical trials of an immunosuppressive drug called azathioprine (Imuran), which researchers believe may delay or even prevent the onset of insulin-dependent diabetes.

Major Gains Made in Islet Cell Transplantation

Scientists have made other important research gains in treating insulin-dependent diabetes, notably through transplants of healthy islet cells to patients with IDDM. In NIDDK-supported research, Drs. Scharp and Lacy transplanted islet cells into a 36-year-old woman who previously received a kidney transplant and whose immune system had been suppressed by medication to decrease the chances of her rejecting the transplanted cells. Within 10 days, the patient no longer required insulin injections, and did not need them for 2 weeks. Although her body began to reject the transplanted cells and supplemental insulin was needed again, this case represents the first demonstration that islet cell transplantation is a feasible approach to controlling insulin-dependent diabetes. More recently, the same investigators reported a second successful islet cell transplant in which the patient required no insulin injections for more than 6 months.

Rejection of transplanted cells may not prove such a barrier in the future if NIDDK grantee Dr. Ali Najj and his colleagues at the University of Pennsylvania in Philadelphia are able to reproduce in larger animals and eventually in human beings the results of their remarkable experiment on rats. In research that experts called "creative and imaginative," Dr. Najj transplanted islet cells into the thymus glands of diabetic rats. The thymus offers protection from immune attack because key immune cells called T lymphocytes develop in the gland, "learning" there which antigens to recognize as "self" and which to attack and destroy as foreign.

Dr. Najj's team injected islet cells along with a serum that contained antibodies to lymphocytes into the animals' thymus glands. The serum destroyed 90 percent of the mature T lymphocytes, causing the thymus to generate new T cells in the presence of the transplanted islet cells. Because the islet cells were present in the thymus as the T cells developed, the new T cells in effect accepted the transplanted cells as

"self." The transplanted islet cells survived to produce insulin, curing the rats' diabetes.

NIDDM Results from Genetic and Environmental Factors

Non-insulin-dependent diabetes, the most common form of diabetes, affects 11 million Americans -- approximately 95 percent of all diabetic men and women. Most often, NIDDM is controlled by diet, exercise, and oral drugs. Like IDDM, it appears to run in families, and researchers believe that genes, together with environmental factors, contribute to the development of NIDDM. Unlike IDDM, however, NIDDM affects a disproportionately higher number of Blacks, Hispanics, Native Americans and native Hawaiians, but no one knows why.

People who develop NIDDM do produce insulin, but for still unexplained reasons, their bodies don't respond to the insulin properly. This so-called insulin resistance is one of the hallmarks of NIDDM, and is probably the genetically determined piece of the NIDDM puzzle.

Insulin regulates how blood sugar is used and stored in the liver, muscles and fat tissue. Ordinarily, it does this by a complex series of chemical events that is still not completely understood. Researchers trying to decipher where the process goes awry have focused on the first step in the pathway, the binding of insulin to its receptor and the genetic factors that might cause insulin resistance. NIDDK's Dr. Simeon Taylor and colleagues have studied the genetic causes of insulin resistance. Using recombinant DNA technology, they identified a number of mutations in the insulin receptor genes of patients with rare syndromes of extreme insulin resistance. Their work illustrates both the complexity of this metabolic process and the many ways it might malfunction. In some patients, genetic mutations cause a significant decrease in the number of insulin receptors on the cell surface. Other patients have a normal number of receptors on their cell surface, but there is a defect in the way these work. In some patients, the receptor is truncated, and cannot perform all of its functions. Alternatively, mutations might cause subtle changes in the structure of the receptor, disrupting the binding process. Mutations also might inhibit the activity of a key enzyme, tyrosine kinase, whose action is necessary for the receptor to transmit a signal across the cell's plasma membrane. Identifying the prevalence of mutations in insulin receptor genes should help clarify how and where disease begins in common forms of NIDDM.

In related research, Dr. Taylor and a second team of researchers found the amino acid sequence of the insulin receptor gene to be normal in several persons with more common forms of resistance. This and research by other investigators suggests that defects in genes that control other parts of the

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insulin response system may be responsible for the development of the more common forms of NIDDM.

Researchers Begin Search for NIDDM Genes

Fifty percent of adult Pima Indians age 35 and older have NIDDM--the highest rate of diabetes in the world. Researchers from the NIDDK and the Indian Health Service have been studying diabetes in the Pimas since 1965 in an effort to obtain a clearer picture of the natural history and evolution of NIDDM. Recently, Dr. Peter Bennett and colleagues at an NIDDK facility in Phoenix, Arizona, began the laborious search for the gene or genes that confer susceptibility to NIDDM.

Several pieces of evidence suggest that genes play a strong role in determining susceptibility to diabetes in the Pimas. Insulin resistance shows strong familial clustering, independent of obesity. Also, the distribution of insulin resistance in the Pimas is trimodal: those affected tend to cluster into three groups--with low, medium, and high levels of insulin resistance--rather than in the typical wide spectrum of distribution seen in the general population. According to the Phoenix researchers, this three-pronged pattern suggests that in the Pimas, a major autosomal gene for insulin resistance may be inherited in a co-dominant manner, that is, a person could inherit two copies of a normal gene, enabling a normal response to insulin; two abnormal genes, resulting in severe insulin resistance; or one of each, causing moderate insulin resistance.

Bolstering the case for a genetic basis of insulin resistance is a recent study conducted by NIDDK researcher Dr. Dave Pettitt, showing that Pima children have insulin resistance decades before the onset of diabetes. In a study comparing 439 nondiabetic Pima children age 6 to 19 with age-matched white children from Rochester, Minnesota, Pima children were found to have blood insulin levels 15 to 20 percent higher than their Midwestern counterparts.

National Cancer Institute

The National Cancer Institute (NCI) contributed to diabetes mellitus research this year through studies of the role of growth factor, called transforming growth factor beta (TGF-beta), in the development of a kidney disease called glomerulonephritis which is sometimes a complication of diabetes.

Dr. Wayne Border, at the University of Utah in Salt Lake City and his colleagues are collaborating with Drs. Erkki Ruoslahti and Lucia Languino of La Jolla Cancer Research Foundation in California, and NCI investigators working under Dr. Michael Sporn.

Glomerulonephritis includes several related diseases that damage the glomeruli, tiny globular structures, each containing a loop of capillaries, where blood filtration occurs in the kidney. These related kidney diseases strike about 100,000 people a year.

In a healthy kidney, the blood passes through the glomeruli, and certain substances are filtered out. During this process, substances useful to the body, such as water and glucose, are reabsorbed into the blood stream, while other substances are collected as urine and excreted. If the glomeruli are damaged, kidney function is destroyed, leading to uremia and death. Glomerulonephritis also contributes to the development of high blood pressure, as the kidneys play an important role in the regulation of blood flow.

The cause of glomerulonephritis is incompletely understood, but the triggering event is often thought to be an immunologic injury to certain cells in glomeruli called sangial cells. The release or activation of TGF-beta during glomerular injury could then lead to the production of certain proteins and to the scarring characteristic of this disorder.

These investigators reported that TGF-beta could make kidney cells in tissue culture increase production of two proteoglycans (molecules composed of sugars and protein), biglycan and decorin in certain cells in the membrane of the glomeruli. This overproduction leads to scarring similar to that seen in glomerulonephritis. The scarring limits the ability of the glomeruli to filter blood. This finding has led the scientists to study whether TGF-beta plays a similar role in the development of diabetes-associated kidney disease.

The researchers found that administration of antibodies to TGF-beta at the induction of glomerular disease suppresses the overproduction of the proteoglycans and dramatically reduces tissue scarring. This finding provides direct evidence of a causal role of TGF-beta in the pathogenesis of glomerular disease and suggests a new approach to the therapy of glomerulonephritis. If successful this could lessen the need for dialysis or transplants.

National Heart, Lung, and Blood Institute

National Heart, Lung, and Blood Institute (NHLBI) research on diabetes mellitus focuses on the disease's role as a risk factor for cardiovascular disease (CVD) and its manifestations in the cardiovascular system. As the population ages and interest expands in studies of cardiovascular disease in women and minorities, in whom the prevalence of diabetes is high, this research takes on more significance and may have greater impact on our overall understanding of cardiovascular disease.

Major Studies Address Diabetes in American Indians and Mexican Americans

The Strong Heart Study is examining cardiovascular disease and its risk factors in three American Indian regional communities in which reported rates of CVD vary both upward and downward from those of the general U.S. population. Some 2,100 of the study's anticipated 4,500 participants have been studied; they range in age from 45 to 74. Diabetes is common in most American Indian groups, with prevalence rates ranging from 2 to 20 times those of the general U.S. population.

The San Antonio Heart Study is examining CVD and diabetes in a population of Mexican-American men and women with varying levels of acculturation to life in the United States. Diabetes is very common in this minority group, especially among those with obesity. The study has found that cardiovascular risk factor abnormalities develop before the emergence of diabetes, a finding that may help to explain the high rates of CVD in those with diabetes. The finding has implications for the development of programs to reduce the risk of CVD in those with a high risk of developing diabetes.

Diabetes Appears To Be a Major Contributor to Vascular Disease

Vascular disease accounts for most of the clinical complications and increased mortality in patients with diabetes mellitus. Among the factors contributing to this are abnormalities of vascular reactivity that result in increased incidence of atherosclerosis (commonly called hardening of the arteries). The blood vessel wall has been found to play a major role in local control of vascular reactivity through the release of many factors that influence blood vessel tone in response to important physiological agents.

NHLBI grantee Babette Weksler and colleagues at Cornell University Medical Center, New York City, have discovered that relaxation of the vessel wall in response to acetylcholine in the aorta is impaired in rabbits with diabetes. This dysfunction follows the production of vessel-constricting chemicals and is likely due to hyperglycemia. Nerve system

disorders also have been found in the arteries of diabetic rabbits.

These studies in a diabetic rabbit model are significant for indicating striking abnormalities in adrenergic nerve function and the blood vessel wall, both of which have important roles in controlling smooth muscle contraction. These abnormalities seem to be important contributors to the development of abnormal vascular reactivity and vascular disease, which are characteristic of diabetes.

National Institute of Dental Research

The National Institute of Dental Research (NIDR) supports a broad program of research on diabetes mellitus, ranging from basic science to clinical trials of improved treatment methods to investigations focused on prevention.

Basic Research Sheds Light on Autoimmune Factors in Diabetes

One of the causes of IDDM is the destruction of the insulin-producing pancreatic islet beta cells by the individual's immunological defense system. NIDR intramural investigators are trying to identify and characterize the autoantigens--normal proteins that the body mistakenly recognizes and attacks as "foreign"--involved in IDDM. Using recombinant DNA technology, intramural researcher Dr. Antonio Toscani and his colleagues recently isolated and cloned two autoantigens from the islet beta cells. One of these proteins has a unique gene sequence not described before. Characterization of these proteins may help researchers understand how islet beta cells are destroyed, resulting in diabetes mellitus.

Matrix Proteins Hold the Key to Kidney Complications in Diabetes

Diabetic nephropathy (kidney disease) is a life-threatening complication of diabetes mellitus. The condition is caused by an overproduction of extracellular matrix proteins (key components of connective tissue) around blood vessel walls. This causes the walls to thicken, impairing the function of the blood vessels and the kidney tissues they nourish. Because these proteins are essential to the early development of the kidney, NIDR intramural investigators Drs. Paul Klotman and Benjamin Weeks are studying them to gain a better understanding of their role both in normal development and in the disease processes involved in diabetes and renal cell carcinoma (kidney cancer). These basic studies have important applications to kidney regeneration and the development of new diagnostic tests and treatments for kidney disease.

Animal Model Will Speed Diabetic Nephropathy Research

Research on diabetic nephropathy has been hampered by the lack of a suitable animal model. NIDR scientists have found an obese rhesus monkey whose condition closely resembles NIDDM in humans. This animal, like humans with diabetes, overproduces extracellular matrix proteins. This model will allow testing of new drugs that may halt or reverse the abnormal thickening of the blood vessel walls in diabetic nephropathy.

National Institute of Neurological Disorders and Stroke

The majority of Americans who have diabetes also have some degree of peripheral nerve damage, or diabetic neuropathy. For two million people, the damage is severe and can cause pain, tingling sensations, and numbness. More threatening, however, is the lack of sensation that often masks injuries, such as foot and leg ulcers, and that sometimes leads to infection, gangrene, and eventual amputation.

Diabetes-related research by the National Institute of Neurological Disorders and Stroke (NINDS) focuses on investigating the mechanisms and causes of diabetic neuropathy and the development of promising new treatments for this serious condition.

Studies Lead the Way for New Treatments

A team of scientists headed by NINDS grantee Dr. Peter J. Dyck at the Mayo Clinic in Rochester, Minnesota, has been studying the epidemiology, causes, mechanisms, and treatments of diabetic neuropathy. This year, Dr. Dyck and his colleagues continued working on the prevailing theory that reduced oxygen and blood supply caused by high blood sugar results in diabetic neuropathy. Using normal rats, the scientists first reduced and then reintroduced normal blood flow in the peripheral nerves (those outside the brain and spinal cord). When blood flow was reintroduced, oxygen inflow was restored. The scientists found that this process resulted in damage to the nerves, leading them to conclude that the reintroduction of oxygen may damage peripheral nerve tissue.

Dr. Dyck and his team have also been investigating a promising drug called aminoguanidine. They have found that the drug prevents many of the blood flow abnormalities found in diabetic neuropathy and is therefore effective against nerve-injuring ischemia (restricted flow of blood). Further studies of aminoguanidine may ultimately result in a promising new treatment.

This year, a team of NINDS grantees led by Dr. Henry Powell of the University of California at San Diego found evidence to support the theory that hyperglycemia--elevated blood sugar--injures the Schwann cells that surround and protect peripheral nerves. The scientists induced a hyperglycemic state in a rat model and observed direct injury to Schwann cells, which in turn produced the symptoms of diabetic neuropathy. Dr. Powell is now working with a new drug called ponalrestat that has been shown to inhibit the metabolic abnormalities associated with diabetic neuropathy. If ponalrestat interferes with the process of Schwann cell injury, an effective new treatment for the disease may result.

Proteins and Nerve Cell Growth Studied

Certain proteins called growth factors are essential to nerve cell development and maintenance. NINDS grantee Dr. Douglas N. Ishii of Colorado State University in Fort Collins is continuing his studies of the role in diabetic neuropathy of a group of these proteins--insulin-like growth factors (IGFs), which help in the development of nerve cell axons. He is also investigating the hypothesis that if diabetic neuropathy is present in the peripheral nervous system, it might be present as well in the central nervous system. Dr. Ishii and his colleagues measured nerve function in the spinal cord of diabetic rats and found that the speed at which nerve messages travel--a measure of the type of nerve damage found in diabetic neuropathy--was decreased. This work is the first conclusive evidence that there is diabetic neuropathy in the central nervous system.

National Institute of Allergy and Infectious Diseases

The National Institute of Allergy and Infectious Diseases (NIAID) conducts and supports research on a variety of disorders of the immune system, including autoimmune diseases such as IDDM. NIAID grantee Dr. J. Donald Capra at the University of Texas Southwestern Medical Center in Dallas and his colleagues have pinpointed two genetic markers that indicate whether a person is likely to develop IDDM. Such information might be used to suggest who should be treated with immune-suppressing drugs in an effort to prevent development of diabetes.

Dr. Capra and his coworkers analyzed the genes governing the production of HLA-DQ proteins (previously discussed in the NIDDK section). When the researchers compared the genetic material of IDDM patients to those of a normal population, they discovered that an individual with an HLA-DQ gene called HLA-DQw1.2 is not likely to develop diabetes. But a person with the HLA-DQw8 gene is six times more likely to develop diabetes than someone without this gene type, unless he or she also has the protective HLA-DQw1.2 gene. HLA-DQw1.2, they concluded, is strongly protective against the development of IDDM. Using genetic markers such as HLA-DQw8 and HLA-DQw1.2 may lead to the ability to identify individuals at high or low risk of developing IDDM.

At a recent workshop jointly sponsored by NIAID, NIDDK, and the National Institute for Child Health and Human Development, researchers noted the substantial progress that has been made in determining who is likely to develop IDDM. Using that information, investigators are now embarking on clinical studies designed to test the effectiveness of immune-suppressing drugs in preventing the development of IDDM in high-risk individuals.

National Institute of General Medical Sciences

The National Institute of General Medical Sciences (NIGMS) supports basic research and research training that provide the foundation for a better understanding of fundamental life processes. This research can supply new knowledge and theories to the disease-targeted programs of other NIH components, including those related to diabetes.

Researchers Clarify Aspects of Insulin Secretion

Scientists led by Dr. Hsiao-Ping H. Moore, an NIGMS grantee at the University of California, Berkeley, are studying how cells sort proteins into secretory vesicles, the minute sacs that release newly made proteins into the bloodstream. This work sheds light on normal protein transport within the cell, and may lead to greater understanding of the production and secretion of protein hormones. Since one of the proteins the scientists are studying is insulin, their research could help clarify the molecular basis of diabetes mellitus.

Insulin is produced in three stages. After the product of the second stage, called proinsulin, is made, it is transported to the Golgi apparatus, a cellular "traffic zone" where proteins are sorted and routed to their final destinations. The exact mechanism for the sorting of protein hormones at this stage is not known. Proinsulin is then sent to secretory vesicles, where it is processed into its mature form, insulin, which then is released into the blood.

Dr. Moore and her associates hope to determine whether proinsulin itself contains the message that directs it to secretory vesicles. Using mutant forms of proinsulin to test whether the altered molecules are targeted to vesicles as efficiently as normal proinsulin, the researchers found that the information for entry into secretory vesicles is contained within proinsulin. However, mutating proinsulin in specific regions did not have a significant effect on its routing, which indicates that the elusive transport signals are not present in these areas of the molecule.

Future experiments will concentrate on identifying the molecular aspects of the movement of vesicles from the Golgi apparatus. This will enhance understanding of the secretion process and its importance in diseases such as diabetes.

National Institute of Child Health and Human Development

The National Institute of Child Health and Human Development has a longstanding interest in research designed to lead to the prevention of IDDM.

Dr. Suzanne Johnson and colleagues at the University of Florida at Gainesville have been analyzing the behavior of children and adolescents with IDDM to ascertain which behavioral patterns are associated with stable and unstable metabolic control. Management of diabetes in children and adolescents is complex, requiring compliance in many different areas.

The investigators analyzed six different components of children's diabetes-control regimen: exercise, insulin injection, diet, glucose testing/eating frequency, calories consumed, and concentrated sweets eaten. Dr. Johnson found that only glucose testing/eating frequency showed an association with stable metabolic control. As the patients got older, control was poorer.

While the patient's age proved to be a strong and consistent predictor of adherence to the regimen and control of diabetes, the poor glucose control exhibited by adolescents may not be caused by their poor compliance. Biological factors associated with the child's physical development, such as puberty, may have major effects on diabetes control.

Gestational diabetes, transient diabetes during pregnancy, also is being studied by NICHD. Clinical studies are being conducted by Dr. Satish Kalhan of Case-Western Reserve University in Cleveland, Ohio, to detect abnormalities in glucose tolerance early in gestation and to relate these to pregnancy outcome.

Dr. Kalhan found that in the 30 cases of gestational diabetes that were studied, two-thirds showed a recurrence of gestational diabetes in their pregnancy. The offspring of the mothers with recurrent gestational diabetes were frequently macrosomic (with large bodies and excessive amounts of fatty tissue) and were at high risk for fetal distress and difficult delivery. The patients with consecutive pregnancies complicated by gestational diabetes were significantly more obese than the women without diabetes in subsequent pregnancy; the women with recurrent cases of gestational diabetes were also significantly heavier in subsequent pregnancy compared with previous pregnancy.

National Eye Institute

Diabetic retinopathy (DR) is the leading cause of new cases of blindness among working-age Americans. About 10 percent of the estimated 12 million Americans who have diabetes also have DR. In this disease, capillaries that nourish the retina lose supportive cells in their walls, balloon out in weakened regions, and leak fluid. This leakage causes swelling in the central part of the retina, which, in turn, reduces vision. As the disease progresses, new vessels grow out from the retina, causing scar tissue to develop along the inner retinal surface. If the scar tissue shrinks, the retina may detach from the back of the eye.

Although NEI-supported research has led to therapies that reduce the risk of vision loss from the ocular complications of diabetes, a long-range goal of the Institute is to find ways to stop the initial processes that lead to these complications. Over the past three decades, research has shown that a class of drugs called aldose reductase inhibitors (ARIs) offers promise of preventing retinopathy and possibly other complications of diabetes.

These drugs inhibit the action of the enzyme aldose reductase, which under diabetic conditions causes harmful substances to build up in tissues such as the retina. NEI research in rats and dogs has shown that when the animals with a diabetes-like disease are given certain types of ARIs from the onset of their disease, their retinal capillaries do not deteriorate and their eyes remain healthy.

Based on this animal research, several pharmaceutical companies are developing and testing ARIs in people with diabetes to determine whether the drugs can block the early ocular changes and thereby prevent the retinopathy. In a multicenter, randomized study, NEI collaborated with Pfizer Inc. to evaluate the ARI sorbinil in patients with DR. The Sorbinil Retinopathy Trial showed that slightly fewer sorbinil-treated patients developed retinopathy than those who were given a placebo, but the small difference was not statistically significant. About 7 percent of the patients, however, developed an allergic reaction to the sorbinil.

Findings from recently completed animal research suggest why sorbinil showed so little effectiveness in the trial. In studies with dogs, sorbinil lacked the potency of other ARIs to prevent development of the disease. When the intramural researchers tested the dogs' blood for sorbinil levels, they found that the strength of the drug was much reduced, which makes them suspect that by the time the drug reaches the retinal tissues, its concentration may be too low to inhibit the action of aldose reductase. Furthermore, when the dogs were given a different ARI in combination with sorbinil and the dosages were increased and given more frequently, the

results improved. None of the dogs on the high-dose combination drug developed retinopathy, as did some of the dogs on sorbinil alone.

Although findings from the Sorbinil Retinopathy Trial show that sorbinil was not significantly beneficial and was toxic to some patients, the trial provided valuable information for future clinical trials with ARIs of different chemical structures. For example, data from the trial established rates at which diabetic complications progress, which is necessary for determining how many patients should be enrolled in a future clinical trial and how long they must be monitored.

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National Institute on Aging

Diabetes mellitus, especially NIDDM, occurs frequently in old age. The National Institute on Aging (NIA) conducts and supports research on the physiological mechanisms involved in diabetes. Results were recently published indicating how body composition and exercise affect risk for diabetes.

Study Shows Benefits of Upper Weight Loss

As people grow older, they often become less physically active and gain weight, particularly in the trunk of the body. Women often become "pear-shaped", with increased fat accumulated in hips and thighs; men tend to become "apple shaped", with thicker waistlines.

This increase in body fat can affect more than appearance. Obese older people are particularly at risk for diabetes, and they develop heart disease at a greater rate. Because weight gain has been shown to increase the risk of these diseases even in young and middle-aged individuals, NIA grantee Dr. Patricia Coon and coworkers at the Johns Hopkins University School of Medicine in Baltimore, Maryland, studied body composition and metabolic function in older obese men. The relationship of age, body composition, and exercise capacity to glucose tolerance, insulin, triglycerides, and cholesterol were measured. A deterioration in glucose tolerance and increased insulin sensitivity are associated with increased risk for both diabetes and heart disease.

Dr. Coon selected a group of volunteers of comparable age, proportion of body fat, and waist-to-hip ratio measurements and then randomly assigned them to either a weight loss or an aerobic exercise training program. Participants in the weight loss program were taught behavioral techniques to reduce caloric intake and were given guidelines for good nutrition. Those in the exercise program rode stationary bicycles, walked, and jogged three times each week but were given weight-maintaining diets. Training programs were based on each individual's aerobic capacity and were supervised by an exercise physiologist.

After 6 months, Dr. Coon and her colleagues found that in the weight loss group, a 12 percent loss of body weight resulted in significant improvements in triglycerides, cholesterol, and insulin levels, and glucose tolerance. The findings indicate that while obesity is an important determinant of metabolic function, glucose intolerance and insulin resistance are associated with upper-body distribution of fat. The men in the weight loss group reduced waist measurements 1 1/2 inches for each inch lost in the hips. Aerobic exercise increased oxygen capacity but did not change the waist-to-hip ratio or percentage of body fat.

Dr. Coon's study indicates that body composition or percentage of body fat is a more important determinant of metabolic function than either age or aerobic capacity. Although weight reduction appears to have a major impact on reducing the risk for diabetes, a combination of weight loss and exercise are considered the best nonpharmacological method of improving glucose tolerance and insulin levels and reducing that risk.

National Center for Research Resources

Shared research facilities provided by the National Center for Research Resources (NCRR) support a variety of studies focused on diabetes. Recently grantees of the General Clinical Research Centers (GCRC) Program described the combined effect of environmental and genetic factors in increasing the risk of developing NIDDM.

Environment May Heighten Inherent Diabetes Risk

Japanese-Americans are at high risk of developing NIDDM, according to NCRR grantees at the University of Washington GCRC in Seattle. Others whose ethnic background or recent cultural experience is non-Western may also be vulnerable. The reason, the researchers believe, is a combined effect of ethnic and family history, lifestyle, and diet.

Grantee Dr. Wilfred Y. Fujimoto explained that many immigrants and extended visitors to the United States are from societies that do not have high-fat diets or the kinds of stress experienced in this country. Also millions of others born in the United States are of a family lineage that might predispose them to NIDDM. When exposed to Western diets and high-stress lifestyle, their backgrounds--recent or ancient--may put them at significant risk of developing NIDDM.

Japanese, for example, may be inherently predisposed toward developing diabetes. This natural predisposition is revealed in the United States, according to Dr. Fujimoto, when Japanese immigrants to this country experience the high sociocultural stress and diets containing large amounts of animal fat and protein.

More than 400 Japanese-American men and women of the Seattle area, ranging from 45 to 75 years of age, were tested for glucose tolerance and a variety of serum components. Computed tomography (CAT) scans were taken to measure subcutaneous and visceral fat deposits in the chest, mid-abdomen, and thigh. The study found that over 50 percent of those studied had abnormal glucose tolerance, while 20 percent of the men and 16 percent of the women had NIDDM--percentages significantly higher than those seen in either native Japanese or Caucasian American populations. The GCRC grantees also observed a link between intra-abdominal body fat and the incidence of diabetes.

National Center For Nursing Research

Research on diabetes supported by the National Center for Nursing Research (NCNR) focuses on helping patients maintain optimum control of their symptoms and minimize the risks for developing psychological and social adjustment problems.

Chronically Ill Children May Have Social Adjustment Problems

Understanding the risks for social adjustment problems in children with diabetes and other chronic diseases, and the role family functioning may play, can help nurses and other health professionals develop better ways to aid adjustment.

NCNR grantees Drs. Kathleen Knafl and Bonnie J. Breitmayer and their colleagues at the University of Illinois College of Nursing in Chicago studied social competence in chronically ill children, many of whom had diabetes. Social competence is defined as the ability to successfully develop and sustain relationships with peers and to function adequately in school. The study included 63 families with a 7- to 14-year-old child who had a chronic illness.

The investigators found that most of the children with chronic illnesses in the study fell within the normal range for social competence. However, the researchers also found a significantly higher incidence of social competence difficulties in all the children than has been documented in a sample of children drawn from the general population.

Since family stress and dysfunction may exacerbate the problems of having a childhood chronic illness, the investigators looked at how individual family members manage the illness and how they helped with the treatment regimen. Parents were asked about the child's social relationships, school participation and performance, and any problem behaviors.

Of the children rated by mothers, 23 percent met the criteria for maladjustment while 29 percent of those rated by fathers did. Most ratings were by mothers, who were more involved in monitoring and treating their children's illness and in communicating with health and school personnel than were fathers. Children with more highly educated mothers were more socially competent, according to the researchers' observations.

In this study, children who were more physically impaired tended to have more adjustment difficulties. As would be expected, children who were rated as energetic and did not appear ill were the most socially competent.

The findings suggest that the largest deficit in children with chronic illness is in social relationships. The results also suggest that the increased risk for social competence difficulties among such children may be ameliorated when they are part of successfully-functioning families.

Outlook

More than a dozen institutes at NIH support scientists with many kinds of expertise whose work continues to advance knowledge about diabetes and its complications. These advances have occurred because of ongoing basic research in cell and molecular biology, immunology and genetics. They have been significant enough to lead diabetes researchers to predict that they will know how to prevent insulin-dependent diabetes by the year 2000. In spite of this progress, millions of Americans continue to suffer the debilitating effects of diabetes. Ending the enormous human and financial toll exacted by diabetes will require the renewed commitment of seasoned researchers and the enthusiasm of a new generation of young scientists willing to take up the search for a cure.

CENTERS FOR DISEASE CONTROL

Diabetes Translation

Center for Chronic Disease Prevention and Health Promotion

In 1987, more than 730,000 new cases of diabetes mellitus were identified in the United States. That same year, there were 6.8 million Americans with diabetes -- an increase since 1980 of approximately one million. Diabetes is a chronic, complex, metabolic disease characterized by high blood glucose levels caused by a deficiency in insulin production, an impairment of insulin utilization, or both. Survey data indicate that the prevalence of diabetes may be underestimated by half.

In 1986, diabetes was the seventh leading cause of death in the United States, and the thirteenth leading cause of potential life lost before age 65. It caused the death of over 37,000 Americans and contributed to more than 50,000 others. We know that this is probably a substantial underestimation, because diabetes is reported on only about half the death certificates of persons who die with the disease, and is listed as the underlying cause on only one quarter of the certificates where it appears.

Individuals afflicted with diabetes face not only a shortened life span, but also the probability of incurring acute and chronic complications. Persons with diabetes spent approximately 11 million days in the hospital. A conservative estimate of the cost attributable to diabetes in 1987 was \$20.4 billion. Even so, the full economic impact is masked because additional medical expenses are often attributed to the specific complications of diabetes rather than to the disease itself.

In 1987, approximately 56,000, or half of all nontraumatic amputations in the United States occurred in people with diabetes, at a direct cost of approximately \$500 million. It is the leading cause of new cases of adult blindness. The disease is not only an independent risk factor for cardiovascular disease; it also interacts with other risk factors--smoking, high blood pressure, cholesterol, obesity, and physical inactivity--so that heart disease is twice as common and more often fatal in people with diabetes than in the general population. The risk of atherosclerotic disease is five times greater in women with diabetes. Approximately 50 percent of people with diabetes have hypertension, compared with 20 percent of people without diabetes.

Diabetes accounts for 9,000, or nearly 30 percent, of the total new cases of end-stage renal disease in the United States each year. Women with diabetes are more likely to experience complications of pregnancy and their babies are more likely to die at birth. Infants of diabetic mothers also have a three-fold increase in the frequency of birth defects, and a five-fold increase in other complications that require intensive medical care in the early days of life.

In an effort to reduce the health and economic burdens of diabetes, the Centers for Disease Control (CDC), in partnership with 26 States and 1 Territory, is conducting a wide range of activities to:

- Implement effective control strategies at the community level
- Expand control strategies on a State-wide level

- Establish consensus concerning standards for patient management and self-care
- Develop networks for rapid translation of important findings of diabetes research into widespread community practice
- Create the operational base upon which intervention strategies can be built
- Evaluate program impact in terms of reduction of selected complications of diabetes

These State programs have been working closely with various public, private, and voluntary organizations, as well as with service delivery programs, to prevent complications associated with diabetes, including blindness and visual loss, adverse outcomes of pregnancy, lower extremity amputations and cardiovascular disease.

The efforts supported by CDC at the State level emphasize the delivery of program services to minority, elderly, and other low socioeconomic groups disproportionately affected by diabetes. To target essential services to those in need, 25 State-based diabetes control programs report some form of third-party reimbursement for outpatient diabetes education, i.e., at least one program in the State is receiving reimbursement from at least one carrier.

The CDC chairs the Financing Coordinating Committee that works with the Health Care Financing Administration and the Health Insurance Association of America to improve essential health care services for persons with diabetes. Committee members include representatives from the American Diabetes Association, the American Association of Diabetes Educators, the American Dietetic Association, and the National Diabetes Advisory Board.

In 1987, in response to the National Diabetes Advisory Board's 1987 Long-Range Plan to Combat Diabetes, Congress appropriated nearly \$2.4 million in additional funds to the diabetes effort at CDC to initiate a more intensive effort to "translate" important research findings rapidly and effectively into widespread clinical and public health practice. Toward that aim, CDC has developed and implemented a number of applied science projects, including:

- Studies to evaluate screening for increased urinary albumin as a risk marker for diabetic renal disease and the short-term efficacy of preventive interventions. Findings will be used to target efforts to prevent or delay end-stage renal disease in diabetics.
- Studies to develop and evaluate comprehensive primary care and public health strategies to decrease risk factors for lower extremity amputation and to improve the preventive behaviors of providers and patients. Findings will enhance programmatic efforts to prevent amputation.
- A study to ascertain the current visual acuity of diabetic patients entered 2 or 3 years ago into programs to prevent visual loss and to determine how well they complied with treatment and examination recommendations. Findings will assist CDC in gauging its impact,

adjusting efforts accordingly, and determining whether or not these efforts are resulting in a lasting change, at least for an intermediate period.

- ▶ Studies to evaluate utilization and cost-effectiveness of pre-pregnancy counseling among women with diabetes to decrease maternal and infant morbidity and mortality.
- ▶ A major multi-year project to develop, demonstrate, and evaluate primary and tertiary preventive interventions to reduce the burden of diabetes. The project, which focuses on community-based interventions in a black population, will address issues related to disability and quality of life.

A revised and expanded publication, The Prevention and Treatment of Complications of Diabetes: A Guide for Primary Care Practitioners, is currently being pilot tested and will be ready for final publication in early 1991. The revised guide provides practical management guidelines for the prevention and treatment of nine major complications of diabetes.

In addition, CDC is introducing an annual surveillance report that will focus on the incidence and prevalence of diabetes and its complications. These reports will help in planning program activities, and will enhance the ability of health agencies to measure the impact of those activities at less expense. CDC is cooperating with three State health agencies to develop similar surveillance systems at the State level.

Diabetes Today is a course recommended in the National Long-Range Plan to Combat Diabetes, 1987. The purpose of the course is to improve dissemination of the existing and emerging knowledge base about all components of an effective community strategy. The CDC has developed the course, with pilot testing completed in September 1990. Implementation will begin in Spring of 1991.

National Center for Health Statistics

DIABETES

Information from the National Vital Statistics System indicates that diabetes mellitus was the seventh leading cause of death in the United States in 1988, accounting for over 40,368 deaths or 1.9 percent of all deaths in the year. Since 1978 the risk of death for this cause has levelled off from an earlier downward trend. The risk of death from diabetes is about the same for males as for females, but over twice as high for the black as for the white population.

The basis for determining the total prevalence of diabetes mellitus in the United States adult population 20-74 years of age was obtained for the first time in the second program of the National Health and Nutrition Examination Survey as an aid to the increased authority of the National Institutes of Health and Centers for Disease Control (Public Law 93-354) for diabetes prevention, control, research and training. The diagnoses for the prevalence estimates were obtained from the physical examination, medical and dietary history, and blood and urine tests conducted as part of the diagnostic glucose tolerance test given to a probability sample of those adult examinees not presently taking insulin. Findings indicate that the total prevalence of diabetes is approximately 6.6%, or two times that for known diabetes. Similar data were collected in the Hispanic Health and Nutrition Examination Survey, and are being collected for the third National Health and Nutrition Examination Survey, which began in October of 1988. NHANES III includes additional laboratory measurements related to diabetes.

Findings from the Hispanic Health and Nutrition Examination Survey indicate a total prevalence of diabetes of 24 percent among Mexican Americans ages 45-74 in the Southwest, of 16 per cent among Cubans ages 45-74 years in the Miami area, and of 26 per cent Puerto Ricans ages 45-74 years in the New York metropolitan area.

In 1976, the National Health Interview Survey (NHIS) collected prevalence data on diabetes by numerous demographic population characteristics. In addition to determining the prevalence of known diabetes in the population, the 1976 NHIS asked for the type of medication and level of knowledge about this condition among individuals reported to have diabetes. Diabetes prevalence data are collected on a continuous basis by the NHIS. Based on data now available from the NHIS, in 1989 nearly 6.5 million persons in the civilian, noninstitutionalized population were reported to have known diabetes, reflecting a rate of 26.6 conditions of known diabetes per 1,000 population.

Extensive data from the 1979-81 NHIS, NHANES II, and other diabetes-related data were included in Diabetes in America, a publication sponsored by the National Diabetes Data Group of the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases of NIH.

According to the 1989 National Hospital Discharge Survey, an estimated 438,000 patients were discharged from short-stay hospitals in the United States with a first-listed diagnosis of diabetes mellitus. The average length of stay for these patients was 7.6 days. Females accounted for 55 percent of the discharges and patients 45 years and over accounted for 70 percent of the discharges. In addition to these patients with a first-listed diagnosis of diabetes mellitus, an estimated 2.5 million patients were discharged with a secondary diagnosis of diabetes mellitus.

ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION

Diabetes Research

National Institute of Mental Health

Diabetes mellitus is a metabolic disorder in which the ability to oxidize carbohydrates is almost completely lost, usually due to faulty pancreatic activity, causing a disruption in the production of insulin. There are two types: Type 1 is insulin-dependent and usually, but not always, has its onset in childhood; Type 2 is adult onset, non-insulin dependent.

The role of the brain in physical disease is studied in both the Intramural Research Program and the Behavioral Medicine Branch of the National Institute of Mental Health which supports research on psychosocial, behavioral and biological risk factors and the interactions in diabetes. NIMH has a strong commitment to research on health and behavior particularly on the examination of biological, psychosocial and behavioral factors and their interactions that impact on the development and course of medical illnesses. Additionally, psychosocial, psychopharmacologic and behavioral treatments and interventions are another focus for behavioral medicine research programs.

Growing research in neuroscience is contributing to our understanding of how the brain "speaks" to the body's organs. Neurochemicals made in the brain, specific behaviors, psychological effects or abnormal genes may all separately and in combination influence disease in the body.

AccomplishmentsGenetic Regulation of Brain Mechanism in Diabetes

Dr. Richard Surwit at Duke University School of Medicine has been studying the role of the central nervous system in the etiology and course of type 2 diabetes mellitus. He has shown that stress, a psychological effect, and stress management can influence the level of high blood sugar. This research has identified, in animal models of diabetes, several important abnormalities in the way the nervous system regulates glucose. Dr. Surwit's group demonstrated that high insulin levels and excessive production of sugar by the liver (major problems in type 2 diabetes) may be caused, in part, by abnormal responses of the pancreas and liver to parasympathetic nervous system stimulation. These studies may ultimately lead to new therapeutic approaches to type 2 diabetes aimed at correcting abnormalities in neural control of glucose metabolism.

Their research on neural control of glucose metabolism in animals led to the discovery that a common laboratory mouse carries the genes to develop diabetes. These genes are expressed when the animal is allowed to overeat. The first series of genetic

investigations indicates that the mode of inheritance of diabetes in these mice is very similar to that in some human populations. Furthermore, the research suggests that a very small number of genes is involved. Specifically, insulin resistance appears to be determined by one or more co-dominant genes and overt diabetes by an additional recessive gene or genes. These studies may ultimately lead to the identification of the genes that cause diabetes and to curative therapies aimed at correcting the defect caused by these genes.

Current Research

Neuroscience of Diabetes

NIMH intramural scientists are involved in basic studies of the biochemistry of insulin and the expression of genes for insulin in the brain and peripheral tissues.

Psychological Predictors in Diabetes

Investigators have begun to identify individual psychological differences that predict the degree to which conventional insulin therapy will establish good control of glucose production in children. Researchers have established that a Type A behavior pattern is predictive of a hyperglycemic response to a competitive stress. Most recently, they have demonstrated a positive correlation between another psychological factor (introversion) and the degree of blood sugar control over an extended period of time.

Mental Health Effects of Diabetes

NIMH researchers are investigating whether adults with insulin-dependent diabetes experience higher rates of cognitive impairment than non-diabetic matched controls. The study is delineating potential risk factors for impairment including sociodemographic, medical and psychiatric factors. Additionally, subgroups at increased risk for cognitive impairment will be identified and specific interventions developed for these populations.

Other NIMH investigators are examining adaptive family processes in diabetes. This knowledge is a vital prerequisite to construction of effective, empirically based primary and secondary intervention programs to enhance and maintain family adaptation, especially in the context of parental dysfunction. In a longitudinal study, NIMH researchers are investigating the complex interplay between ego development and family environments in juvenile diabetics. This study has significant implications for clinical interventions through clarifying the impact of chronic illness upon adolescents and their families as well as to elucidate developmental influences upon illness management.

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

DIABETES MELLITUS

The purpose of the Agency for Health Care Policy and Research (AHCPR) is to enhance the quality, appropriateness, and effectiveness of health care services and to improve access to that care. This is accomplished through the establishment of a broad base of scientific research and through the promotion of improvements in clinical practice and in the organization, financing, and delivery of health care services. The AHCPR also is responsible for facilitating the development, review, and updating of clinically relevant guidelines for specific conditions and treatments. As the focal point of Federal efforts in medical effectiveness and health services research, the AHCPR seeks to create and disseminate new knowledge and better understanding of the processes by which health services are made available and how they may be provided more efficiently and effectively.

Medical Treatment Effectiveness/Outcomes Research

Studies supported by the Agency for Health Care Policy and Research show that there are often wide variations in the types of health care furnished to apparently similar populations within and across geographic areas. Of even more concern, the research also shows that often these variations are associated with different outcomes. The Medical Treatment Effectiveness Program (MEDTEP) of AHCPR has significance for saving and extending lives, improving the quality of health care for Medicare beneficiaries and other patients, increasing and maintaining patients' functional abilities, and conserving resources. These benefits can occur as a result of new investment in the development and dissemination of scientific knowledge about patient outcomes, allowing health care providers and their patients to make more informed decisions about treatment options.

Health services research in this country and elsewhere indicates that variations in the use of health care services and procedures reflect the complex interaction of clinical, social, environmental, economic, and psychological factors that shape the relationship between patient and provider. Variations are appropriate if they arise from differences in the needs and choices of individual patients, and if the alternative patterns of care are known to be equally effective and efficient. However, the "practice styles" of physicians account for many of the differences observed in the care of patients with similar conditions, and providing physicians with information about the outcomes of care reduces these variations considerably. Practice styles are most variable for those health care conditions and procedures associated with greatest uncertainty and controversy among physicians. Research on patient outcomes and the dissemination of its findings will help to reduce these uncertainties and resolve these controversies.

FY 1990 marked a significant expansion in the AHCPR effort to develop reliable and comprehensive data on the effectiveness of different medical treatments. Eleven Patient Outcomes Research Team (PORT) projects were funded as part of MEDTEP through the Agency's Center for Medical Effectiveness Research (CMER). These projects are multiyear and multidisciplinary studies focused on variations in clinical practice and outcomes for a particular medical condition. Each PORT project is designed to identify and analyze the outcomes and costs of alternative practice patterns for a specific condition, determine the best strategy for treatment of clinical management, and develop and test methods for reducing inappropriate variations. One of the eleven PORTs supported by the AHCPR's Medical Treatment Effectiveness Program focuses on diabetes.

FY 1990 MEDTEP Projects Relating to Diabetes:

Sheldon Greenfield, M.D., New England Medical Center
 "Variations in the Management and Outcomes of Diabetes"
 Grant No. HS 06665

Diabetes is a major source of health care costs and disease burden. The annual incidence of Type II diabetes is approximately 320 per 100,000 in persons over 20, and approximately 8,800 per 100,000 persons over 65 are affected. In 1982, diabetes accounted for 35,000 deaths and 5,800 new cases of blindness. It is associated with a high proportion of end-stage renal disease and non-traumatic amputations, as well as sharply increased risk of hypertension and ischemic heart disease.

The major objective of this Patient Outcome Research Team (PORT) is to develop a comprehensive, prospective, longitudinal database tailored to the requirements of medical effectiveness in chronic disease, specifically Type II diabetes. Research on chronic diseases is complex because care extends over many years, patients use multiple, mostly outpatient, providers and multiple types of health care resources, and quality of care depends heavily on interpersonal (e.g., educational, motivational) as well as technical aspects of care. The data system will be implemented in three large health care delivery organizations in Boston, Indianapolis, and Portland, where a total of approximately 6,000 patients will be enrolled and followed for four years. A combination of survey data, chart abstraction, and claims data will be linked for analysis of variations in practice, utilization, expenditures, and patient outcomes. Based on literature review, decision analysis, and analysis of the database, the PORT will develop practice recommendations regarding optimal technical and interpersonal care associated with the outcome of principal interest, patients' quality of life. Educational interventions, planned as randomized controlled trials, will aim to improve specific physician practices with respect to utilization, expenditures, technical and interpersonal quality of care.

Ty Hartwell, Research Triangle Institute

"Community Health Care Models for Diabetes Prevention and Control" Intra-Agency Agreement #AHCPR 90-16 (with CDC)

An estimated twelve million Americans have diabetes, with over 650,000 new cases identified each year. Diabetes and its complications are more prevalent among blacks, Hispanics, and Native Americans. In 1987, patients with diabetes spent approximately 27 million days in the hospital with total health care costs of about \$20.4 billion. Recent strides in understanding diabetes and how to prevent or delay its complications have not been fully applied, leaving a significant disparity between the actual and attainable patterns of morbidity, mortality, and cost.

Using data obtained from diabetes patients, primary care providers, and hospitals, this project will: evaluate the community-level burden of diabetes mellitus and the quality and effectiveness of health care services for persons with diabetes; develop community-level models for incorporating current practice guidelines into medical and self-care; and develop and demonstrate community health promotion strategies. The project seeks to establish whether health care and promotion activities that are thought to be efficacious are effective in preventing morbidity and mortality, especially in communities with large minority populations.

Two communities will be selected to serve as intervention and control sites. One community will develop and implement a health care model for patients with established diabetes. Changes in the incidence of diabetes-related morbidity after institution of the model will be contrasted with the second community. The second community will be the site for an obesity prevention and control program intended to reduce the prevalence of obesity and incidence of diabetes. For this intervention, the first community will serve as the control.

Klea D. Bertakis, M.D., University of California, Davis
"A Comparison of Practice Styles and Health Outcomes"
 Grant No. HS 06167

The primary objective of this research is to evaluate the components of physician style that influence outcome and patient satisfaction. Specifically, the study is designed to test the following study hypotheses:

- o There are measurable differences in practice styles between family physicians and internists.
- o These differences in practice style generate differential costs of care and different health outcomes for specific diseases.

- o Patient satisfaction will correlate with practice style rather than health outcomes.

New nonpregnant, adult patients will be randomized to receive care primarily from either a family practice or an internal medicine physician. Multiple outcome assessments will be used by the investigators, including analysis of videotaped physician-patient encounters, measures of patient satisfaction, glycosylated hemoglobin, SMA-20's, blood pressure measurements and other vital signs (e.g. weight). Patients will be followed for up to two years and total health care utilization, both at the University of California (UC) Davis and elsewhere, will be measured.

Patients with diabetes are not being specifically targeted for inclusion in the study, but since diabetes mellitus is a fairly common reason for adult patients to seek care, particularly among the disadvantaged groups who make up the majority of the clinic population seen at the University of California (UC) Davis Clinics, it is probable that a substantial subgroup of the 500 patients enrolled in the study will indeed have diabetes. For these patients, there will be measures of patient satisfaction, physician-patient interaction, health care utilization, results of the Medical Outcomes Study Short Form, as well as glycosylated hemoglobin determinations.

INDIAN HEALTH SERVICE

Diabetes Program

The National Commission on Diabetes recommended, and Congress authorized and funded in 1979, the IHS Model Diabetes Health Care Program. The Program was subsequently authorized in Section 204 of P.L. 100-713. The program has developed and evaluated effective and culturally acceptable methods to reduce the severity of the disease and the expense to the IHS of related medical services.

Five initial project sites were chosen to represent different types of IHS facilities and different population groups. The Claremore (Oklahoma) Indian Hospital is a multi-service referral facility located off the reservation. The Fort Totten (North Dakota) Health Center is a small outpatient clinic on the reservation. The Albuquerque (New Mexico) program serves both urban and rural Indians while Sacaton and Winnebago serve populations which represent typical regional settings.

Two additional projects were initiated in FY 85. The Maine Intertribal Diabetes Prevention and Care Project is a coordinated effort among four tribes under contract to IHS. The Lummi Service Unit is the base for a team providing service to northwest Washington. During FY 87, two new Centers of Excellence were developed: one in Browning, Montana and one in Tuba City, Arizona. These sites are developing culturally relevant approaches to diabetes education among the Plains Indians and the Navajo. Two "model" sites have received recognition of the Diabetes Education Programs through the American Diabetes Program Association.

Additional budget mark-ups in FY 88 provided the funds for three new programs in northern Minnesota, Alaska, and Arizona which are now operating. Multidisciplinary teams have been placed at each site to upgrade preventive services and to develop a comprehensive diabetes care plan that includes routine screening for complications, patient education, nutrition counseling, and attention to related conditions such as hypertension, urinary tract infections, and foot care. Considerable progress has been made at these sites in delivering high-quality, culturally acceptable diabetes care. In FY 90, Zuni (New Mexico), Ft. Berthold (North Dakota), Warm Springs (Oregon), Unitah & Ouray (Utah), and United Indian Health Services of California completed the projects authorized in Section 204.

Transfer of effective treatment strategies from model projects to service units was an ongoing priority in 1990. Diabetes Control Officers in all areas provided surveillance, training, and program reviews to ensure timely application of techniques piloted in the model sites. Materials developed by the "model" sites have been very popular system wide. In 1990 audit data from 98 facilities was collected to monitor quality assurance in

diabetes care. Eighteen one-time initiatives were funded to improve screening and treatment of retinopathy to reduce blindness from diabetes. Improvements in foot care practices have reduced amputations in Alaska and these techniques are being applied in other facilities.

Progress is also being made in community involvement. A training module for Community Health Representatives is available. A resource manual is available to guide practitioners counseling patients who are using the commodity foods programs. A physician orientation package is available and an orientation for health educators is being developed. IHS is implementing a Type II Diabetes teaching curriculum and developing the Indian-oriented material related to the curriculum. Criteria for the National Diabetes Education Standards were modified for IHS and are being used to guide and evaluate quality education efforts.

A major cooperative initiative with NIH has been initiated with a conference involving diabetes researchers, Indian tribes, and IHS. The proceedings are being prepared for scientific publication and planning grants are now being submitted to NIH for further research on diabetes in Indians.

Surveillance data for amputations will be refined as a major initiative to decrease amputations is initiated in 1991. Strengthening Area Diabetes Control activities in 1991 will enable areas to introduce strategies to provide protective footwear to high risk patients. IHS techniques are being shared with Canada and with developing countries that are beginning to experience high rates of diabetes.

DEPARTMENT OF HEALTH AND HUMAN SERVICES
REPORT ON POPULATION AND FAMILY PLANNING ACTIVITIES

A REPORT TO THE
HOUSE COMMITTEE ON APPROPRIATIONS

Prepared by
The Office of Population Affairs
March 1991

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I

INTRODUCTION

This report describes the population research, family planning and population education activities of the Department of Health and Human Services.

Population research and family planning activities in the Department of Health and Human Services include support of service--making family planning information and services available and accessible; training--meeting the professional and lay manpower needs in health, social services, and education; research--promoting and supporting research and research training in the biomedical and broad behavioral aspects of fertility, sterility, population dynamics, and program implementation, and public education--increasing opportunities for public understanding of human sexuality, population education and information about family planning.

Under the Social Security Amendments of 1967 (Pub. L. 90-248), subsidized family planning services were made available through a variety of sources to some of those who want but cannot afford them. The Social Security Amendments of 1972 (Pub. L. 92-603) required that family planning services be offered and provided promptly upon request to all recipients of Aid to Families with Dependent Children (AFDC) and of medical assistance (Medicaid). The Social Services Amendments of 1974 (Pub. L. 93-647) added a Title XX¹ to the Social Security Act (SSA). Under the Social Services Amendments of 1976 (Pub. L. 94-401), States had the option of providing family planning services under Title XX to individuals regardless of their income. The major provisions of Pub. L. 92-603 continued in effect until Title XX was amended by Pub. L. 97-35, establishing the social services block grant program effective October 1, 1981².

The Family Planning Services and Population Research Act of 1970 (Pub. L. 91-572) established Title X of the Public Health Service Act, the major direct source of Federal support for family planning services programs.

¹ As initially enacted, SSA Title XX applied to the 50 States and the District of Columbia. Family planning social services for Guam, Puerto Rico, and the Virgin Islands were available under SSA Titles I, IV, X, XIV, and XVI.

² The participants in the Title XX social services block grant program are the 50 States, the District of Columbia, Guam, Puerto Rico, the Virgin Islands and the Commonwealth of the Northern Mariana Islands.

Legislative Highlights

1. On January 2, 1968, the Social Security Amendments of 1967 (Pub. L. 90-248), which included the Child Health Act of 1967, were enacted. This Act established categorical project grants for family planning services and required that not less than six percent of the monies appropriated for Maternal and Child Health under SSA Title V be available for family planning services. This same legislation required that under SSA Title VI-A, the AFDC program, family planning services were to be offered in all appropriate cases. Acceptance of such services was voluntary.
2. On December 24, 1970, the Family Planning Services and Population Research Act of 1970 (Pub. L. 91-572) was enacted, establishing Title X of the Public Health Service Act. This Act was passed to assist in making comprehensive voluntary family planning services available to all persons desiring such services.
3. Title X funding authorizations were extended by Pub. L. 93-45 in 1973, Pub. L. 94-63 in 1975, Pub. L. 95-83 in 1977, Pub. L. 95-613 in 1978, Pub. L. 97-35 in 1981 and Pub. L. 98-512 in 1985.
4. On October 30, 1972, the Social Security Amendments of 1972 (Pub. L. 92-603) were enacted. This Act made it mandatory to inform all recipients of AFDC of the availability of family planning services and to provide or contract for services to all eligible persons voluntarily desiring them. This Act imposes a penalty of one per cent per anum on the Federal share of AFDC funds on States which fail to provide them to eligible persons desiring them. In addition, the Act increases the Federal share of matching for family planning services under Title VI-A--AFDC--to 90 percent from 35 percent. It also made family planning services a required service for all Title XIX--Medicaid--programs, subject to a 90 percent Federal matching rate.

5. On January 4, 1975, the Social Services Amendments of 1974 (Pub. L. 93-647) were enacted. These Amendments established SSA Title XX which placed major responsibility upon the States to develop their social services programs to be responsive to the needs of the citizens of each State. Title XX continued the requirement under Pub. L. 92-603 that family planning services be offered and provided promptly to those AFDC recipients requesting such services. States had the option of providing family planning services on the basis of income eligibility status. In addition, States were required to provide three services to recipients of Supplemental Security Income (SSI) payments to the aged, blind and disabled. Family planning could have been one such service. The Federal share of matching was at the 90 percent rate.
6. On September 7, 1976, Pub. L. 94-401 amended SSA Title XX, adding a provision that States may provide family planning services to individuals regardless of their income.
7. On November 10, 1978, the Health Services and Centers Amendments of 1978 were enacted. This Act established under Titles VI, VII and VIII within the Office of the Assistant Secretary for Health and in consultation and coordination with the Deputy Assistant Secretary for Population Affairs, programs to prevent or reduce unwanted and repeat pregnancies among adolescents. These programs were to enable pregnant adolescents to obtain proper care and to become productive independent contributors to family and community life. In 1981, this program was incorporated into the Maternal and Child Health Block Grant.
8. On August 13, 1981, Congress amended Title XX of the Social Security Act by enacting social services block grant legislation under Pub. L. 97-35. This block grant legislation became effective October 1, 1981. States were given greater flexibility in administering their social service programs than they had under the previous Title XX programs. Any requirements with regard to eligibility for services and what services to cover are now left to the discretion of the States.

SUMMARY OF DHHS PROGRAM ACTIVITIES BY OPERATING AGENCY

PUBLIC HEALTH SERVICE

Office of the Assistant Secretary for HealthOffice of Population Affairs

Supports delivery of family planning medical services, counseling and referral.

Supports short-term training for family planning professional health personnel.

Supports family planning information and education activities.

Supports social research in the area of family planning service delivery.

Office of International Health

Policy development and coordination for international health program and activities.

National Institutes of HealthNational Institute of Child Health and Human Development

Supports basic biomedical research on reproductive physiology and contraceptive development.

Supports social research on the causes and consequences of population structure and change, including factors affecting fertility and family planning.

Food and Drug Administration

Sponsors and monitors research on contraceptive safety.

Maintains a contraceptive reporting system.

Reviews and approves applications for clinical investigations of contraceptive drugs and devices.

Reviews and approves new drug and new device applications for marketing.

Health Resources and Services AdministrationBureau of Health Care Delivery Assistance

Supports family planning services as well as consultation and technical assistance.

Bureau of Health Professions

Supports professional education programs for physicians and nurses.

Supports Family Nursing research.

Indian Health Service

Provides family planning information and education services.

Centers for Disease ControlCenter for Chronic Disease Prevention and Health Promotion

Conducts epidemiologic field investigations of contraceptive methods and analysis of pregnancy-related morbidity and mortality.

Provides training for health professionals.

National Center for Health Statistics

Conducts social research on fertility, family planning, and the reproductive health of American women.

OFFICE OF HUMAN DEVELOPMENT

Office of Policy, Planning and Legislation

Supports family planning services, including counseling and information and referral services through the Social Services Block Grant. Also supports social services projects and evaluations that address teen pregnancy prevention.

SOCIAL SECURITY ADMINISTRATION

Health Care Financing AdministrationBureau of Program Operations

Provides family planning services and supplies including sterilization services, to categorically needy persons through the Medicaid program.

II

PUBLIC HEALTH SERVICE

Office of the Assistant Secretary for HealthOffice of Population Affairs

The Office of Population Affairs (OPA), under the direction of the Deputy Assistant Secretary for Population Affairs (DASPA), administers the Title X Family Planning Program and the Title XX Adolescent Family Life Program.^{1/} In addition to these program administration activities, the DASPA advises the Secretary, through the Assistant Secretary, on policy and new legislation; participates in legislative and fiscal planning; and prepares reports on departmental and inter-departmental activities for the Secretary and the Congress. The DASPA also works in cooperation with other Federal agencies, as well as with other concerned organizations, in the areas of population research and family planning services, training and education.

Within the OPA, the Office of Family Planning administers family planning activities authorized under the "Family Planning Services and Population Research Act of 1970" (P.L. 91-572), which established Title X of the Public Health Service Act. Title X authorizes project grants for voluntary family planning services, and grants and contracts for continuing professional education for family planning services personnel, for service delivery improvement research, and for family planning information and education. Categorical project grants under Title X of the PHS Act represent the major Federal source of direct funding for family planning services.

The broad purposes of Title X are stated in the law as follows:

1. To assist in making comprehensive voluntary family planning services readily available to all persons desiring such services;
2. To improve administrative and operational supervision of family planning services;
3. To enable public and nonprofit private entities to plan and develop comprehensive programs for family planning services;
4. To develop and make readily available information (including educational materials) on family planning to those desiring such information;
5. To evaluate and improve the effectiveness of family planning service programs; and

^{1/} Grant administration for the Family Planning Program is now being carried out in HRSA, under the direction of the DASPA.

6. To assist in providing trained personnel needed to carry out family planning programs.

The primary target group for Title X family planning services is the estimated 13.6 million low income women of childbearing age (low income being defined here as having an income below 150% of the poverty level).

Approximately 20 million women have at least one family planning visit each year. More than 7.1 million women receive services from organized family planning--3.7 million from Title X funded programs. Another 12.8 million receive services from private physicians.

The Office of Family Planning allocates Title X service funds to the ten DHHS regional offices, which in turn allocate these funds among their 85 grantees, request and approve applications for Title X service grants, and monitor grantee performance. A Regional Program Consultant for Family Planning serves as coordinator for family planning activities in each Region. Title X currently funds about 4,000 family planning clinics throughout the United States and its territories.

The primary objectives of the program have been to continue to provide high quality family planning services, to improve the efficiency and effectiveness of family planning projects, and to encourage the involvement of the family in the provision of family planning services. Staff development programs, information and education activities, and service delivery improvement research have been directed to support the attainment of these objectives.

Title X training programs are designed to provide personnel with the skills and knowledge necessary for the effective delivery of family planning services. Training is provided in structured and non-structured settings and includes in-service education, staff development, and continuing education activities that are innovative, self-paced, self-instructional or mediated with newer technological advancements in the field of education. The current national training priority areas are 1) clinic management, 2) counseling and client education, 3) family involvement, 4) management of infertility, including adoption, 5) natural family planning (NFP), 6) program management, 7) prevention of sexually transmitted diseases (STDs), including HIV infection and AIDS, 8) adolescent abstinence from premarital sexual activity, 9) male involvement and 10) prevention of substance abuse.

In Fiscal Year 1990, ten general training grants, one in each of the DHHS regions, were awarded. These grants are aimed at providing training for all personnel who are employed in Title X funded clinics such as managers, mid-level providers, physicians,

professional and technical staff and clerical/receptionist staff. All of the general training grantees were provided with supplemental awards to support training activities on HIV/AIDS.

The five obstetric/gynecology or women's health care nurse practitioner programs are specifically designed for registered professional nurses who are employed in family planning clinics to become nurse practitioners. Approximately 142 nurse practitioners completed programs for Title X clinics in Fiscal Year 1990. Nurse practitioners provide 60-70 percent of all medical encounters in family planning clinics. They are an essential part of the family planning services delivery system because they increase a clinic's capacity for providing high quality, cost-effective health care services to more clients. All Title X funded nurse practitioner programs are nationally accredited by the American Nurses' Association. Since the beginning of the training program in 1973, Title X funded training projects have produced more than 2,938 nurse practitioners.

The major activities supported under the Title X information and education program include the operation of the Family Life Information Exchange and the development of information and education materials for family planning clients and clinic staff. During FY 1990, the Information Exchange distributed over 1 million pieces of educational, informational or administrative material including patient education pamphlets, information and education bulletins for clinic staff and bibliographies. Prominent among these materials was a guidebook entitled The Adoption Option, developed by OPA for pregnancy counselors, and a booklet, "Adolescent Abstinence", which was developed by the Association of State Family Planning Administrators with funding from the OPA. A very useful document about Pap smears was developed for clinicians. Improving the Quality of Clinician Pap Smear Technique and Management, Client Pap Smear Education and the Evaluation of Pap Smear Laboratory Testing: A Resource Guide for Title X Family Planning Projects, has been much requested. A popular brochure entitled "Your Contraceptive Choices For Now, For Later", was also distributed. Because of the large number of requests, the pamphlet, "Many Teens are Saying 'NO'", was again reprinted. Additionally a Spanish language version of this pamphlet was distributed.

The focus of the Service Delivery Improvement (SDI) Program continues to be enhancement of the delivery system, particularly at the clinic level. In addition to direct technical assistance efforts in this regard, the SDI research program funded projects to obtain knowledge needed by family planning service providers to better understand service delivery processes and how such processes may be influenced in the desired direction. Three continuation research grants were supported, covering an array of topics--male involvement in family planning, the utility of a

computerized counseling aid, and the effects on service provision of integrating family planning services and sexually transmitted disease services. A SDI research contract was also awarded to make available computer readable data on family planning in the form of a data archive.

INTERNATIONAL ACTIVITIES

The Office of International Health (OIH), a staff office to the Assistant Secretary for Health, has primary responsibility in the Public Health Service for overall policy guidance and coordination of PHS international health programs and activities, on behalf of the Assistant Secretary for Health. OIH assures that policy issues related to population and family planning are appropriately addressed in the governing bodies of multilateral organizations (e.g. the World Health Organization and the United Nations Children's Fund), and it promotes involvement in activities of those agencies throughout the year. OIH also promotes cooperation with other countries through a variety of U.S. bilateral agreements. Involvement of the PHS in implementing selected aspects of the U.S. foreign assistance program through the Agency for International Development has been an integral part of the PHS international programs for over two decades.

At the United Nations Children's Fund (UNICEF) Executive Board Meeting in April 1990, the U.S. Delegation again encouraged UNICEF to place greater emphasis on child spacing. UNICEF is now, as part of its safe-motherhood program efforts, including increased attention to child spacing.

PHS personnel (NIH, CDC and FDA) serve on numerous Steering Committees and Task Forces of the World Health Organization, including such groups as the Task Force on Male Methods of Fertility Regulation, the Task Force on Post-Ovulatory Drugs, the Task Force on Vaccines for Fertility Regulation, the Task Force on Safety and Efficacy of Fertility Regulating Methods, the Task Force on Behavioral and Social Determinants of Fertility Regulation, the Task Force on Sperm Function Regulating Agents, the Task Force on Safety and Efficacy of Fertility Regulating Methods, the Working Group on Technical and Managerial Guidelines on AIDS and Family Planning Methods, and the Working Group on HIV Infection and Pregnancy.

Cooperative and collaborative efforts have continued with the World Health Organization regarding the development of safe and efficacious methods of fertility regulation and other population-related issues. For example, the National Institute of Child Health and Human Development (NICHD) has undertaken extensive screening of chemicals synthesized by WHO. In turn, WHO has done some of the clinical testing of contraceptive products developed either by the Institute alone or through joint funding. Additionally, NICHD is contributing to the funding of a multinational study of breast cancer in 13 countries which are participating in the WHO Collaborative Study of neoplasia and Steroid Contraceptives.

PHS bilateral cooperation in the areas of population and family planning has continued with India. The seventh Indo-U.S. Workshop on Reproduction and Contraception Research will be held in India in March 1991. Two joint workshops will be held in 1991--one on epidemiology and reproduction and the other on "In Vitro Systems for Assay of Reproductive Hormones and for Reproduction Research." These activities will be funded through the U.S.-India Fund for Educational, Cultural and Scientific Cooperation, under which PHS has an allocation of funds.

NICHD's extramural research program is supporting a number of population-related studies. A study funded by NICHD in Canada will improve our understanding of normal human embryonic development and the processes that lead to fetal wastage and developmental abnormalities. A project in Guatemala is studying the effects of familial behavior and the local availability of maternal and child health services on the health and survival of children in Guatemala in the late 1980's. NICHD-supported investigators are conducting demographic research in Taiwan. This study is providing insights into fertility decline with the evolution of the country and society.

Under a reimbursable services agreement with the Agency for International Development, the Centers for Disease Control continued to provide logistics assistance, perform contraceptive requirements analyses, conduct program evaluations, evaluate and collect program data, provide information and data to AID-assisted countries, and assist in the implementation of management support systems. During 1990, CDC staff collaborated on the survey design and/or analysis of data from reproductive health surveys in fourteen countries--Belize, Brazil, Chile, Costa Rica, Ecuador, El Salvador, Guatemala, Haiti, Jamaica, Somalia, Swaziland, Taiwan, Turkey and Venezuela. CDC worked with Costa Rica on their national women's health study, which provided data to analyze the relationship between the use of oral contraceptives and reproductive system cancers. Training support was provided eight countries. For example, a five-day training workshop on family planning logistics management for the Ministry of Health was held in Botswana. In Taiwan, on-site training for Ministry of Health staff was provided on data analysis of the national Family Planning-Maternal Child Health Survey. Overall, assistance was provided to 33 countries throughout the year. Additionally, in collaboration with WHO Family Health International, CDC continued work on a manual on reproductive health epidemiology and methodology for use in workshops in developing countries.

NATIONAL INSTITUTES OF HEALTH

National Institute of Child Health and Human Development

FAMILY PLANNING AND POPULATION RESEARCH

The National Institute of Child Health and Human Development (NICHD) has the primary responsibility for the research programs in the population sciences of the Department of Health and Human Services. Section 448 of Title IV of the Public Health Service Act as amended by P.L. 99-158 authorizes the Institute to conduct and support "research, training, health information dissemination, and other programs with respect to maternal health, child health, mental retardation, human growth and development, including prenatal development, population research, and special health problems and requirements of mothers and children." Section 1004 of Title X of the Public Health Service Act, as extended, authorizes the Department of Health and Human Services to award grants and contracts for "research in the biomedical, contraceptive development, behavioral, and program implementation fields related to family planning and population."

NICHD's Center for Population Research (CPR) oversees the primary Federal extramural program in population research. Support is provided through grants and contracts for:

- fundamental biomedical research in the reproductive sciences related to problems of human fertility and infertility;
- development of safe and efficacious methods for fertility regulation;
- evaluation of the benefits and risks of current contraceptive methods;
- demographic and behavioral sciences research on the causes and consequences of population structure and change.

The Center's support includes research training programs to promote the development of manpower needed for population research. In addition, the Center encourages the communication of research information in the population sciences and promotes international cooperation in this area.

Program Seeks Better Understanding of Reproduction

A major goal of the reproductive sciences program is to further basic scientific knowledge about reproduction that will lead to useful medical applications. Accordingly, efforts are focused on basic scientific research in reproductive medicine, endocrinology, genetics and immunology, developmental biology, and the reproduction process. This knowledge is directed at: 1)

alleviating human infertility; 2) easing or curing human reproductive diseases and disorders; and 3) discovering new leads for improved methods of fertility regulation.

Dr. Richard P. Woychik, an NICHD grantee at Oak Ridge National Laboratory in Oak Ridge, Tennessee, is carrying out research designed to improve methods of inserting mutations to make transgenic mice. He initially developed a new method for rapidly extracting and analyzing DNA to study the inheritance of transgenes (inserted genes), and now Dr. Woychik is injecting DNA into fertilized eggs to produce transgenic mice. Currently, he has produced 150 lines of transgenic animals, is testing another 56 for germ line (reproductive cell) inheritance and is processing another 411 potential founders (recipients of transgenes) for the presence of transgene sequences. He expects to generate 200 lines per year. Mutagenesis screening already has identified several lines of these animals that seem likely to contain insertional mutations that cause skeletal abnormalities and death of an embryo. These mutants are expected to be important for elucidating the mechanisms that control the various phases of reproduction including mutants that affect gametogenesis (the development of male and female sex cells), fertilization, and development of the embryo from preimplantation through implantation in the womb.

Male Contraceptive Appears Promising

The contraceptive development program supports clinical trials and laboratory studies aimed at developing and improving methods of fertility regulation for both men and women that are safe, effective, reversible, and acceptable to various population groups. Research goals include the development of new drugs and devices to regulate fertility in both sexes, improved methods of drug delivery, and better barrier methods of contraception.

Dr. Ronald S. Swerdloff, an NICHD contractor at UCLA-Harbor General Medical Center in Torrance, California, is conducting long-term clinical studies in male volunteers with the "Nal-Glu" luteinizing hormone-releasing hormone (LHRH) antagonist (a substance that nullifies the normal action of another, in this case, LHRH). LHRH is a hormone produced in the brain that regulates reproductive processes. The findings to date indicate that spermatogenesis (sperm formation) can be arrested more readily with this drug than with previously investigated drugs such as LHRH agonists (substances that stimulate the same physiologic response as, in this case, LHRH), various progestins and androgens. The "Nal-Glu" antagonist is a prototype drug, and ongoing studies are necessary to determine whether this approach to male fertility regulation is viable. The men in this study must be given androgen substitution therapy (male sex hormones) in order to maintain libido. Results of these studies strongly suggests that the LHRH antagonists are a sound approach for male fertility regulation,

provided that more potent compounds can be discovered and more practical methods for drug delivery can be developed.

Risk of Cancers from Oral Contraceptives Evaluated

NICHD's contraceptive evaluation program funds the Nation's largest directed research endeavor on the medical effects of contraceptive drugs and devices available in the United States. It has supported some of the Nation's largest studies of health in reproductive-age American women and families. The goal of the program is to compare how various contraceptive methods affect current and long-term fertility and to document any medical side effects. Research is also supported on how barrier contraceptives may prevent disease as well as contraception. Other studies examine reproductive health issues that have multiple determinants; diseases of the reproductive system (rather than disorders of reproduction) are the primary focus.

Phyllis A. Wingo, M.S., at the Centers for Disease Control (CDC) in Atlanta, Georgia, is heading the efforts to further analyze data from the Cancer and Steroid Hormone (CASH) Study, which was supported by NICHD through a contract with CDC. The CASH Study, conducted in 1981 and 1982 and analyzed through 1990, recorded information on every case of breast, endometrial, and ovarian cancer occurring in 10 regions, including some entire states, among women ages 20 to 54. Nearly 4,700 cases of breast cancer and a similar number of controls were obtained in this study, comprising approximately 10 percent of the U. S. population base. The recent analyses are using three age categories rather than adjusting for age. Among women ages 20 to 34 years at diagnosis, those who had at any time used oral contraceptives had a relative odds of 1.4 for breast, endometrial, and ovarian cancer, while the relative odds for such women ages 35 to 44 years was 1.1 and the relative odds for women ages 45 to 54 was 0.9. The youngest women had consistently elevated risks for these cancers, and the oldest women had consistently decreased risks, for all measures of oral contraceptive use. Ms. Wingo and her colleagues interpret their data as reassuring and recommend no change in current practices for prescribing oral contraceptives. Because of recent changes in the upper-age limit recommendations for pill use, as well as changes in pill formulation, they recommend continued epidemiologic surveillance of users. Previous findings from the CASH Study showed that nationally, age-specific ovarian cancer risks are higher among the women in the age groups never exposed to oral contraceptives, which supports assumptions about the protective effects of the pill for this cancer. For endometrial cancer, there is even more dramatic evidence of a decrease in incidence over time in the cohorts of women with ready access to the pill. An even larger decrease in endometrial cancer was demonstrated in older women (born before 1930), reflecting a decrease in unopposed estrogen (a contraceptive containing only estrogen) for post-menopausal hormone use or the addition of progestin to estrogen replacement therapy.

Demographic and Behavioral Sciences

NICHD's demographic and behavioral sciences program focuses on the size, rate of growth, and composition of our Nation's most valuable asset, its population. Research projects address fundamental questions related to the growth and distribution of our population, and the relationship of this to individual and societal welfare.

Dr. Denise B. Kandel, an NICHD grantee at Columbia University in New York City, has been examining the relationship of drug use to sexual activity and premarital fertility by analyzing data from the youth cohort of the National Longitudinal Survey, which is partly funded by NICHD. Controlling for other important risk factors, reported prior use of cigarettes, alcohol, marijuana and other illicit drugs was found to greatly increase the risk of early sexual activity for adolescents. Compared with those who used none of these substances prior to the first sexual intercourse, the risk of engaging in sexual intercourse by age 16 is 1.4 and 1.8 times higher for male and female alcohol users, respectively, .27 and 3.5 times higher for male and female marijuana users, and 3.4 and 4.9 times higher for male and female users of other illicit drugs. The study showed that the greater the degree of drug use and the earlier the reported onset of drug use, the greater was the probability of early sex. Dr. Kandel also explored whether prior drug use has an effect on the occurrence of premarital teen pregnancy, or on the decision to terminate such a pregnancy. A correlation was found only among white teens. Among them, the risk of premarital pregnancy is nearly four times higher for those who have used illicit drugs other than marijuana compared with those with no history of prior substance use. Once a young white woman has become pregnant out of wedlock, if she has a history of illicit drug use, she is more likely to report having terminated the pregnancy.

Future Directions of Family Planning and Population Research

Reproductive Sciences

Studies in reproductive medicine will continue to seek solutions to human infertility and reproductive disorders. Specific research areas may include diagnosis, mechanisms, treatment, and prevention of infertility, endometriosis, polycystic ovarian syndrome, and reproductive consequences of infections, including sexually transmitted diseases. Reproductive genetics and immunology studies will focus on the genetic basis of fertility and reproductive disorders, immunologic infertility, and the potential of immunocontraception. Reproductive endocrinology research will study the functions of the hypothalamus, the pituitary gland, the gonads, and the genital tract, mechanisms of hormone action, and blastocyst implantation. Research concerning the developmental biology of reproduction includes the developmental biological aspects of gametogenesis, fertilization, preimplantation

development, initiation of placenta formation and implantation as central aspects of mammalian reproduction. Studies in reproductive biology will continue to explore the regulatory and modulatory roles of the various growth factors and other substances, such as intragonadal peptides, involved in reproductive processes.

Contraceptive Development

Clinical trials of luteinizing hormone-releasing hormone (LHRH) antagonists will be supported to ascertain the potential of these drugs for regulating fertility. Other clinical studies will be initiated with new long-acting implants and injectables, as well as new transdermal patches, to determine their suitability as contraceptives. With regard to barrier methods of contraception, support will be provided for the evaluation of new disposable diaphragms, for research on the development of new spermicides, and for studies of new types of condoms for both males and the females. In the area of drug development, the synthesis and testing of LHRH analogs will be continued, the synthesis of male antifertility drugs will be expanded, and the screening of compounds for antifertility activity will be continued.

Contraceptive Evaluation

Research on the epidemiology of the pill and other synthetic sex hormones will include studies of the medical and metabolic side effects of the pill, postmenopausal estrogens and progestins, and oral contraceptives developed in foreign countries. Research also will be supported on the ability of barrier contraceptives to prevent sexually transmitted diseases (STDs), pelvic inflammatory disease and its sequelae, AIDS, and cervical cancer. Research on contraceptive safety will focus on the medical indications for selecting an optimal contraceptive method and on ways to improve the delivery of that method to reduce possible complications. Epidemiologic studies will be done to assess the safety and efficacy of non-contraceptive drugs, medical devices, and surgical procedures.

Demographic and Behavioral Sciences

Research will continue to be supported on the antecedents and consequences of adolescent sexuality to learn more about how young people deal with sexual behaviors and their attendant risks, including AIDS and other STDs. The study of fertility trends and their determinants and consequences will continue to be a major focus, including emphasis on the behavioral determinants of fertility and problems such as unintended pregnancy and STDs. Further studies will be funded regarding sexual behavior as it relates to STDs, particularly human immunodeficiency virus (HIV) infection, and contraceptive use, both as a method of fertility regulation and as a prophylactic against disease. Research on

family and household structure, including intergenerational family relationships, will continue to be supported, including aspects such as how cost and availability of child care may affect the employment and fertility of women. Research on migration will be continued to increase our knowledge about how this important force shapes the population structure of American communities. Other studies related to population and family planning will target infant mortality, low birth weight and child health.

FOOD AND DRUG ADMINISTRATION

FAMILY PLANNING

The Food and Drug Administration (FDA), authorized by the Food, Drug and Cosmetic Act of 1938 as amended, approves contraceptive drugs and devices for safety and effectiveness before they are marketed and maintains surveillance over them after they are marketed.

FDA involvement in population research and family planning services is directed toward:

Using its regulatory responsibility to assure the safety and effectiveness of contraceptive drugs and devices;

Sponsoring and/or monitoring the progress of research necessary to carry out the Agency's regulatory responsibilities relating to contraceptive safety and efficacy;

Maintaining a reporting system which serves as a clearinghouse for information concerning adverse reactions associated with contraceptives;

Providing expert advice to the pharmaceutical industry and the academic community in the conduct of studies to obtain data on the safety and efficacy of contraceptive drugs;

Providing information to the public about the safety, efficacy, and proper use of contraceptive drugs and devices through educational materials and labeling.

Advising the Agency in these activities are FDA's Fertility and Maternal Health Drugs Advisory Committee (FMHDAC), which participates in revising contraceptive labeling and in updating guidelines for clinical investigations of contraceptive drugs, and the Obstetric and Gynecological Device Panel which has parallel functions, with oversight of contraceptive devices.

The Investigational Device Exemption (IDE) regulation, implemented in 1981, allows sponsors with approved protocols the freedom to test the safety and efficacy of Investigational devices on human subjects. Currently, two different IDEs are active with protocols approved to study the safety and effectiveness of two models of cervical caps for contraceptive purposes. The studies are closely monitored by the bioresearch monitoring program and the sponsor's required annual reports are thoroughly reviewed.

FDA continues to assess the risk to fetal development from exposure to ionizing and non-ionizing radiation. The Agency promotes consumer and professional education programs to encourage prudent use of diagnostic radiation examinations of

pregnant women. Examples of these activities include publication of recommendations for methods to minimize diagnostic nuclear medicine exposure to the embryo, fetus, and infant; and, preparation and distribution of a poster for display in physicians' offices, clinics, and radiology departments to remind pregnant women about the dangers of X-ray.

In response to growing interest and concerns, FDA monitors video display terminals to determine presence of radiation hazards to pregnant women. Although no radiation hazard has been identified, FDA continues to monitor these devices through a program of testing and surveillance.

FDA has continued an aggressive effort to determine the effects of ultrasound on the developing fetus. The Agency is working with the American Institute of Ultrasound in Medicine to develop educational materials directed to health professionals and consumers using fetal Doppler Ultrasound. The educational information for health professionals will contain instructions on how to know and control acoustic output of equipment during diagnostic procedures. Materials for patients will provide risk and benefit information enabling patients to make a decision about using fetal Doppler Ultrasound.

FDA's Epidemiology Branch conducts comparative analyses of birth defect data from both exposure cohort and defect registry studies as well as drug experience case reports and other sources. For these analyses, the possible association of spermicides, oral contraceptives, and other fertility-related drugs with birth defects is monitored constantly.

Prior to passage of the 1976 Medical Device Amendments, FDA authority related to intrauterine devices (IUD) was limited to the misbranding or adulteration of IUDs. As a result of these Amendments, however, IUDs not classified as drugs were placed under the control of the FDA Center for Devices and Radiological Health, and they are now subject to review for safety and efficacy.

Final regulations, published in 1980 to implement the 1976 Amendments, provided for the classification of non-drug IUDs, tubal occlusion devices, and hysteroscopic devices for female sterilization as Class III Premarket Approval devices. Classified into the Class II, Standards category were: abortion devices, condoms, laparoscopic, and culdoscopic devices for female sterilization, and diaphragms. Finally, fertility prediction devices were classified into Class I, General Controls category. These devices use basal body temperature and cervical mucus as a means to determine ovulation.

FDA approves new types of non-drug IUDs, new types of tubal occlusion devices, and hysteroscopic devices for female sterilization for safety and effectiveness before they are marketed and maintains surveillance over such devices after they

are marketed. Devices that were already on the market prior to the passage of the Medical Device Amendments were allowed to remain on the market without submitting safety and effectiveness data until they were classified. For Class III devices, FDA must allow at least a 30-month grace period before initiating a procedure to call for the submission of safety and effectiveness data.

Such submissions for non-drug IUDs were called for in 1985. Two preamendments device IUDs were withdrawn voluntarily from the market; the Safe-T-Coil in 1982 and the Lippes Loop in 1985. In 1986, Searly stopped the sale of its Copper-7 and Copper-T IUDs in the U.S. because of potential vulnerability to liability. One drug IUD, the progestasert, is still available and the Copper IUD called T380A, was approved in 1984 and marketed in 1988. No non-drug IUDs are currently being marketed.

In October 1987, FDA required the submission of safety and effectiveness data for tubal occlusion devices that are attached to the outside of the fallopian tubes (bands or clips). Since then, FDA has received data for two of those devices and the Obstetrics and Gynecology Devices Panel has recommended that FDA conditionally approve both of them.

On December 19, 1990, the Agency announced approval of an implantable contraceptive that protects women from pregnancy for up to 5 years. The implant consists of a fan-like arrangement of six silicone rubber rods--the size of small matchsticks--containing a hormone, levonorgestrel, which is also an active ingredient in some oral contraceptives. Wyeth-Ayerst Laboratories, will market the product under the name of Norplant. Wyeth-Ayerst has also received marketing clearance from FDA for trocar, a device like a big needle used to place the six capsules under the skin. The trocar will be included in the kit with the Norplant rods.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Maternal and Child Health Bureau

FAMILY PLANNING

The Maternal and Child Health Bureau is involved in the provision of family planning services through the support of individual States which have chosen to provide such services as part of the Maternal and Child Health Block grant. States have responded to service needs in the family planning area in ways which reflect the particular circumstances of each State. Many States have combined Title X and Maternal and Child Health activities into a coordinated health care focus. Among the States, the degree of financial support for family planning services from the MCH Block Grant varies a great deal. Information on this topic is not required in the Block grant annual reports, and therefore data is not available on this subject. Federal Maternal and Child Health staff provide consultation and technical assistance concerning family planning programs as part of their general responsibilities to assist States in development of comprehensive maternal and child health care systems.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Bureau of Health Professions

Family Care

Training and educational activities supported by the Bureau through its grantees with respect to health issues affecting women fall within several reporting categories. Maternal and child health activities emphasize the enhancement of training in high risk pregnancies, dealing with adolescent pregnancies, and generally improving OB/Gyn curricula. Child/family abuse activities also focus on problems related to spousal abuse, and information has recently begun to be gathered for sexually transmitted disease components incorporated into the training of physician assistants. At least three Physician Assistant training programs incorporate women's health initiatives which particularly assist disadvantaged women. This training includes pre/post partum care and midwifery.

In FY 1990, the Nurse Practitioner and Nurse Midwifery Program awarded \$4,442,914 to 28 schools to develop similar programs. While the programs supported under both authorities have much in common, Nurse Practitioner programs stress health promotion and maintenance and Advanced Nurse Education projects stress acute care.

The Nursing Special Project program awarded \$996,124 for activities in family care. These projects included support for improvement of clinical nursing practice through the incorporation of health promotion and health maintenance concepts during all stages of the life cycle within the family in nursing centers.

The Advanced Nursing Education Program awarded \$576,088 to three schools in FY 1990 to support programs designed to educate nurses to work with family groups. This care is comprehensive and may follow the family or family member from health and the home, rehabilitation and, hopefully, back into the community.

Women's Health Initiatives

In FY 1990, under the section 786(a) Family Medicine Residency program, nine grantees indicated training initiatives in this area. Four of these grantees received a total of \$159,719 for development and expansion of curriculum in high risk OB/Gyn and prevention and management of teenage and other high risk pregnancies. St. Joseph's Hospital received \$83,500 of the total funds for the purpose of revamping their OB/Gyn curriculum. It is estimated that 95 residents among these grantees will benefit from this improved training.

Child/Family Abuse Activities

In FY 1990, nine General Internal Medicine and General Pediatrics Residency program grantees indicated activities in child/family abuse, and requested a total of \$25,234 specifically for this purpose. The Boston City Hospital also indicated that their faculty development program includes a child/family abuse component.

Under section 736(a) Family Medicine training, one predoctoral program offers child abuse educational experiences, as does one residency training program. No specific funds were requested by these grantees for efforts in this area.

The Area Health Education Center program awarded a total of \$106,543 to seven of the eight projects who are offering educational training in the area of child/family abuse. The largest award was made to the University of Medicine and Dentistry of New Jersey (\$74,923) for its special initiative in this area. The projects indicated that 7,635 individuals would be impacted by these activities.

Finally, four Physician Assistant Training programs are offering training to an estimated 73 students in the area of child/family abuse. Only one grantee requested specific funds (\$300) for their activities.

Adolescent Health Activities

In FY 1990, the Division of Medicine awarded a total of \$374,321 to 57 grantees specifically to support educational activities in adolescent medicine. These efforts are estimated to impact approximately 83,013 individuals.

Nine Family Medicine Residency grantees indicated that an estimated 208 residents would receive training in adolescent medicine, but specific funds for this experience were not requested. One Family Medicine Predoctoral Program grantee also offers an educational component in adolescent medicine, but did not indicate a specific amount of funds for this area. One Family Medicine Faculty Development grantee has included adolescent medicine in its program activities.

Under the General Internal Medicine/General Pediatrics Residency program 25 grantees indicated training activities in adolescent medicine. Six of these programs received total funds of \$139,073 specifically for these activities which would impact approximately 300 residents. Three Faculty Development programs are focusing on adolescent medicine.

The Area Health Education Center program had 12 projects with adolescent health curricular activities. A total of \$234,313 was awarded to these programs, with the largest award (\$38,467) to the Medical College of Ohio AHEC program for their special

initiative in this area. The AHEC programs indicated that their educational interventions would impact approximately 82,288 individuals, including students and populations in the areas served by the projects.

Five programs to train Physician Assistants under new Section 788(d) indicated that an educational component would be offered in adolescent medicine, which will benefit an estimated 215 trainees. One grantee indicated that \$935 of their award was directed toward this activity.

One AIDS Education and Training Center Program project offers training on the impact of HIV/AIDS epidemic on the adolescent population.

DEPARTMENT OF HEALTH AND HUMAN SERVICES
INDIAN HEALTH SERVICE

FAMILY PLANNING

The Indian Health Service (IHS) provides comprehensive, informed family planning services to all American Indian and Alaska Native men and women who request such services. The goal of these activities is to assure that all American Indian and Alaska Native children are wanted and born to healthy mothers and are born well. A very important part of the effort is that appropriate technical information and services be presented in a culturally acceptable and effective way.

Specific activities for adolescent and pre-adolescent groups are developed and implemented to reduce unplanned and adolescent pregnancies. Effective educational activities and programs geared at enhancing the self-image and esteem of Indian and Native Youth are integrated into the IHS health care delivery system.

Efforts to increase and coordinate existing services to infertile couples continue. Infertility services and adoption services in coordination with other agencies are provided with limited resources.

The IHS does not have a budget line item for family planning. These services are provided as part of the overall comprehensive health care service program of the IHS.

Moyer Material - FY 1992

CENTERS FOR DISEASE CONTROL
Center for Chronic Disease Prevention and Health Promotion
Population and Family Planning

The reproductive health activities of the Centers for Disease Control (CDC) are targeted at public health problems associated with pregnancy, infant health, and fertility control. These activities include epidemiologic studies and surveillance that measure the patterns and trends of reproductive health outcomes and identify ways of reducing health risks. The CDC is also involved with the development and transfer of survey, epidemiologic, and evaluation technology to State and local health department programs.

The CDC conducts epidemiologic studies of the medical consequences of fertility control methods. Currently, more than 40 million women in the United States have used oral contraceptives at some time in their lives. However, the long-term effects of oral contraceptive use are not completely known. The CDC, in collaboration with the National Institute of Child Health and Human Development, conducted a large-scale epidemiologic study to answer questions relating to oral contraceptive use. This study focused on the association between oral contraceptive use and the risk of breast, endometrial, and ovarian cancers.

Results indicate that women who have used oral contraceptives are approximately half as likely to develop ovarian and endometrial cancer as women who have never used them. Results from the study also indicate that oral contraceptive use does not increase a woman's overall risk of breast cancer. However, further analyses of the relationship between oral contraceptive use and breast cancer suggest that the risk of breast cancer for women who use oral contraceptives (OC) may vary by age. Among women aged 20 to 34 years at diagnosis or interview, those who had used OCs had a slightly increased risk of breast cancer compared to women who had never used OCs. Among women aged 45 to 54 years, OC users had a slightly decreased risk of breast cancer. Although there were no statistically significant trends of increasing or decreasing risk with increasing duration of OC use, the youngest women consistently had elevated risks and the oldest women consistently had decreased risk.

The CDC has reevaluated the risk of pelvic inflammatory disease associated with use of the intrauterine device (IUD). Results from a reanalysis of a large epidemiologic study suggest that women at low risk for sexually transmitted diseases may have little additional risk of pelvic inflammatory disease from IUD use. This information has been useful for family planning providers to help advise potential IUD users.

Another major area of investigation related to the medical consequences of fertility control is the study of early and late sequelae of tubal sterilization. This multicenter, prospective study is following 12,000 women over 5 years to better characterize the health consequences of female sterilization, which is the second most prevalent method of contraception among U.S. women. Results of long-term followup on the first 8,000 women in CREST found that 3.1 percent of the subjects reported sterilization regret at 5 years after the procedure. The strongest predictor of regret was young age at sterilization. Approximately 2 per 1,000 sterilized women had undergone sterilization reversal by 5 years postprocedure. The cumulative probability of hysterectomy increased by slightly over 1 percent per year of followup and reached 6 percent at 60 months after sterilization. Overall, the amount of menstrual pain, spotting, and bleeding were found to be increased by the fifth year after sterilization, after adjusting for baseline menstrual dysfunction.

Epidemiologic analysis of the incidence and causes of pregnancy-related morbidity and mortality in the United States continues to be a major CDC activity. Ectopic pregnancy surveillance data for 1987 show that the rate of ectopic pregnancy continues to increase. Preliminary analysis of these data was published in CDC's Morbidity and Mortality Weekly Report (MMWR) in June 1990, and a detailed surveillance report will be published in early 1991. A case-control study of ectopic pregnancy has been completed and data are currently being analyzed. This study was designed to explore the potential etiologic role of specific sexually transmitted diseases, prior induced abortion, smoking, and other personal health habits. Detailed data for induced abortions for 1988 were collected. A preliminary report was published in November 1990, and a surveillance summary will be published in the spring of 1991. In cooperation with State health departments and the American College of Obstetricians and Gynecologists, CDC conducted a retrospective surveillance of all pregnancy-associated deaths for 1979-1986 and continues to conduct prospective surveillance and investigation of all pregnancy-related deaths beginning with 1987. Findings from the retrospective surveillance were published in December 1990 and revealed that black women continue to have a maternal mortality rate 3 to 4 times higher than that of white women and that women who died of pregnancy-related complications were less likely to have had adequate prenatal care than the overall population of women delivering live or stillborn babies. A review of ectopic pregnancy deaths concurrent with induced abortion was completed and published in the April 1990 issue of The American Journal of Obstetrics and Gynecology. Analysis revealed that the mortality rate due to ectopic pregnancy concurrent with induced abortion was higher than that due to ectopic pregnancy in general. Analysis also revealed that the rate of ectopic pregnancy among women seeking induced abortion was 10 times lower than that among women carrying their pregnancy to term.

Since 1969, CDC has collaborated with State health departments to compile the only official national surveillance reports on the number and characteristics of women obtaining induced abortions. Final statistics for induced abortions occurring during 1986-1987 and preliminary statistics for induced abortions occurring during 1988 were published in the Morbidity and Mortality Weekly Report. When compared with similar measures obtained in 1985, the rates and ratios of induced abortion did not change significantly. Most women obtaining abortions continue to be younger than 25 years (58 percent), white (65 percent), unmarried (80 percent), and with one or no previous live births (76 percent). Most abortions were performed during the first trimester, i.e., at or before 12 weeks of gestation (88 percent), and by curettage (97 percent). States are now submitting data for abortions that occurred during 1989.

The CDC provides major technical and programmatic assistance in family planning and maternal/child health programs to States, Federal agencies, and other organizations. A particularly significant area of assistance focuses on clinic management activities using models and techniques originally developed and applied to family planning clinics. The Patient Flow Analysis (PFA) system, designed and developed by CDC, has been used extensively to improve the efficiency of family planning clinics. The system has been adapted for use with a microcomputer to enhance its transfer to State and local health departments. A generic version of this system has been developed, expanding its use to other types of outpatient clinics. The PFA technique has been tested by the Social Security Administration (SSA) for use in their client setting to improve services to clients in local SSA offices.

The CDC's Clinic Management Unit (CMU) continued its work of transferring clinic management technology to States during 1990. Technical assistance and consultation was provided to existing clinic management initiatives in Florida and Kentucky. Both States are implementing management changes in many of their public health clinics. Florida is beginning a major service integration project to more effectively utilize its public health resources to meet the needs of its service population. Kentucky is working to integrate a major management information system into its public health service delivery system. CMU input into these activities has been significant.

A statewide clinic management initiative was also begun in South Carolina during 1990. The CMU staff trained both State and local health department staffs, completed PFA studies, and held group analysis sessions with clinic staffs. The South Carolina clinic management staff is now working with the CMU staff to implement management changes identified as appropriate in public health clinics and to expand the clinic management effort statewide. Additional statewide work is in the planning stage with Missouri.

Initial planning for clinic management activities in New York City was begun in 1990, and follow-up consultation with the Los Angeles County Health Department, Patient Services Improvement Program was also begun during this last year.

The CDC provided technical assistance to the New York State Department of Health for developing a statewide reproductive health needs assessment utilizing telephone survey methodology. The survey was conducted from October 1988 through January 1989, among 1,910 never-married and married women aged 15 to 44; it will provide valuable information on patterns of contraceptive use, use of family planning services, infertility problems, smoking, and need for family planning services. These data will be used by the New York State Health Department to assess the reproductive health care needs and practices of women throughout the State and to plan appropriate family planning and reproductive health programs and services. Data analysis was completed in fiscal year 1990 and a final report will be issued in early 1991.

Under a Memorandum of Understanding with the Indian Health Service, CDC provided technical assistance to population-based risk behavior surveys (with emphasis on reproductive health) among four Native American populations in Oregon (Warm Springs), Washington (Tahaloh Service Unit tribes), Montana (Fort Peck), and New York (Oneida). Staff also participated in an evaluation workshop, hosted by the Warm Springs Reservation, on the Native American Surveys completed to date. Participants included tribal representatives from five Indian nations.

The CDC also provides technical assistance on medical, epidemiologic, and research issues in support of the Title X Family Planning Program through a Memorandum of Agreement with the Office of Population Affairs. A key accomplishment in 1990 has been the development of a report intended to provide guidance to family planning providers concerning male and female sterilization. Other projects included technical reviews of specific documents upon request.

CENTERS FOR DISEASE CONTROL
National Center for Health Statistics
Family Planning Information

The major data activity of the National Center for Health Statistics (NCHS) in the area of family planning is the National Survey of Family Growth (NSFG). This survey is designed to provide national statistics on the fertility, family planning and reproductive health of American women in the childbearing ages.

The NSFG provides data on a wide range of specific topics related to childbearing and reproductive health in the United States:

- o Trends in premarital sexual activity and contraceptive use among teenagers.
- o The characteristics of adoptive parents and of women who relinquish babies for adoption.
- o Pregnancy outcomes, the planning status of pregnancies and intended future births.
- o Trends and group differences in sterilization, infertility, pregnancy loss, and breast-feeding.
- o The contraceptive methods used by women and their partners, and the use-effectiveness of those methods.
- o Use of family planning and infertility services (both public and private).
- o Knowledge and prevalence of AIDS and other sexually transmitted disease such as chlamydia and genital herpes.
- o Use of child-care services, and the work experience and occupation of mothers in relation to their childbearing.

The First and Second Cycles of the survey were conducted in 1973 and 1976, respectively, and were based on samples of women 15-44 years of age; never-married women were excluded. More than 100 NCHS reports and public use data tapes for further scientific research have been released.

Interviews for Cycle III were taken in late 1982 and early 1983, and the sample included women 15-44 years of age regardless of marital status categories. A public use data tape from Cycle III, for scientific research, was released in 1984 and an overview of the principal findings has been published. At least 63 reports and articles based on Cycle III have been published, including five advance Data reports, and seven reports in the Vital and Health Statistics Rainbow Series. Series 23 (which is

part of the Rainbow Series) reports have been published on Contraceptive Use; Services for Family Planning and Infertility; Fecundity, Infertility, and Reproductive Health; Married and Unmarried Couples; Sample Design and Methodology; and Health and Aspects of Pregnancy and Childbirth. Journal articles have examined topics such as trends in contraceptive use, the effectiveness of contraceptive methods, adoption, infertility, pregnancy outcomes, and teenage sexual activity.

Data collection and data preparation for Cycle IV were completed in 1988 and a public use data tape was released in February 1990. Interviews were completed with 8,450 women 15-44 years of age across the country. Six advance data reports were released in 1990. A detailed report on the sample design will be published, and others are in preparation for publication in 1991.

A telephone reinterview of the women interviewed in 1988 was conducted in 1990 to update selected program-relevant statistics, to evaluate the reliability of selected items in the original interview, and to obtain some additional data on such topics as adoptions and sexually transmitted diseases. The telephone reinterview adds a longitudinal dimension to the basic survey to study behavior changes relative to fertility and reproductive health.

Cycle V of the NSFG is scheduled for 1992/93, and is expected to be based on a sample of women initially interviewed in the National Health Interview Survey (NHIS) in 1991. This opens innovative opportunities for obtaining prospective information on issues concerning reproductive health from two surveys for the same sample of women. Telephone reinterviews of women in the Cycle V sample are projected for 1994 and 1996.

The survey provides important baseline and evaluation data for a variety of health programs. The value of the data from the survey is reflected in the funding support given by such sister agencies as the National Institute for Child Health and Human Development and the Office of Population Affairs. Results from Cycles III and IV have provided fundamental data for monitoring the specific decade objectives for family planning in the Department's program for "Promoting Health and Preventing Disease." Cycle IV has provided baseline data for health objectives for the year 2000 regarding adolescent pregnancies and sexually transmitted diseases, and Cycle V will provide data for progress evaluation of these objectives.

CENTERS FOR DISEASE CONTROL
International Health Activities

Under a reimbursable services agreement with the Agency for International Development, CDC continued to provide logistics management assistance, including contraceptive requirements analyses; conduct program evaluations, including reproductive health surveys; evaluate and collect program data, and provide information and data to AID-assisted countries contributing to the improvement of service delivery systems. During FY 1990, assistance was provided to 34 countries, including 14 in Latin America, 11 in Africa, 6 in Asia, and 3 in the Near East. Major program effort went into programs in Brazil, Ecuador, El Salvador, Guatemala, Mexico, Botswana, Kenya, Mauritius, and the Philippines.

THE OFFICE OF HUMAN DEVELOPMENT SERVICES

The Office of Human Development Services' (OHDS) primary mission is to administer social service programs that address the needs of target populations which include children, youth, families, the developmentally disabled, Native Americans and the elderly. HDS provides technical and financial assistance to States and communities for programs that protect vulnerable children and adults, help families stay together and enable low-income and handicapped people to become self-sufficient.

Social Services Block Grant

The Office of Policy, Planning and Legislation, staff office to the Assistant Secretary of OHDS, is responsible for the administration of the social services block grant program (SSBG), the major source of Federal funding for social service programs in the States. Public Law 97-35, enacted August 13, 1981 amended title XX of the Social Security Act to establish the SSBG program under which formula grants are made directly to the 50 States, the District of Columbia, and the eligible jurisdictions (Puerto Rico, Guam, Virgin Islands, American Samoa and the Commonwealth of the Northern Mariana Islands) for use in funding a variety of social services best suited to the needs of individuals and families residing within each State.

In fiscal year 1990 a total of \$2.8 billion was allotted to the States and the jurisdictions under the SSBG. The Federal government makes allotments under a formula based on each State's population. Each State has the flexibility to determine what services to provide, who is eligible to receive services, and how to distribute funds among the various services offered within the State. Thus, under the SSBG, family planning services are provided at a State's option.

Under the SSBG, each State must submit a pre-expenditure report to the Secretary on the intended use of the funds. The statute requires that the report include information about the types of activities to be funded and the characteristics of the individuals to be served. An analysis of the fiscal year 1989 pre-expenditure reports shows that 26 of the 56 States and eligible jurisdictions provided family planning services under their social services block grant programs. Family planning services are administered by the States and may include: information on available resources, personal counseling, and referral for medical care and follow-up. OHDS does not have the specific eligibility and expenditure data on State family planning activities as the SSBG program does not include detailed reporting requirements for such services.

HEALTH CARE FINANCING ADMINISTRATION

Family Planning

Title XIX provisions require States to provide medical assistance to the categorically needy. In general, these are individuals who meet the financial eligibility requirements of a related cash assistance program - Aid to Families with Dependent Children and Supplemental Security Income. If they choose to, States may also provide medical assistance to a number of optional groups including the medically needy - individuals whose income exceeds the categorically needy but is not enough to pay for their medical care.

Family planning services were originally included in the Medicaid program as a State option. However, P.L. 92-603, enacted in October 1972, made coverage of family planning services for the categorically needy mandatory upon the States. This law also increased the rate of Federal financial participation for family planning services and associated administrative costs for both categorically and medically needy to 90 percent (rather than the lower percentage authorized for most other Medicaid services).

Current law requires States to furnish family planning services and supplies, directly or under arrangements with others, to Medicaid recipients of child bearing age (including minors who can be considered to be sexually active) who desire such services and supplies. The scope of family planning services varies among the States. Many States offer a comprehensive range of services to eligible individuals, while others limit family planning services to those furnished by or under the direction of a physician.

Title XIX regulations describe specific parameters for the funding of Medicaid sterilizations, including requirements for informed, voluntary consent of an individual who is at least 21 years of age. Although Federal regulations do not specifically describe other services which may be covered as family planning services, the Medicaid Bureau has published a Financial Management Review Guide for Family Planning Services for use by HCFA regional office staff. The guide lists, by CPT-4 and ICD-9-CM codes, those procedures which may be claimed as family planning services, and those that may not.

HCFA has determined that \$227.2 million was expended by the States and the Federal government for family planning services in FY 1989. Approximately \$68.2 million was spent for sterilization and an estimated \$159.0 million for all other family planning services (expenditures and recipients under Medicaid for fiscal years 1989 through 1996 are reflected in Tables HCFA-1 and HCFA-2).

TABLE HCFA-1

ESTIMATED FEDERAL, STATE, AND LOCAL
FAMILY PLANNING EXPENDITURES UNDER TITLE XIX, FY 1989 - FY 1996

(IN MILLIONS OF DOLLARS)

	<u>FY 89</u>	<u>FY 90</u>	<u>FY 91</u>	<u>FY 92</u>	<u>FY 93</u>	<u>FY 94</u>	<u>FY 95</u>	<u>FY 96</u>
Total Expenditures	\$227.2	\$252.7	\$281.1	\$311.2	\$342.8	\$375.8	\$410.0	\$447.2
Sterilization Services	68.2	75.8	84.3	93.4	102.9	112.7	123.0	134.2
Other Family Planning Services	159.0	176.9	196.8	217.8	239.9	263.1	287.0	313.0

TABLE HCFA-2

ESTIMATED FEDERAL, STATE, AND LOCAL
FAMILY PLANNING EXPENDITURES UNDER TITLE XIX, FY 1989 - FY 1996

(IN THOUSANDS OF PERSONS)

	<u>FY 89</u>	<u>FY 90</u>	<u>FY 91</u>	<u>FY 92</u>	<u>FY 93</u>	<u>FY 94</u>	<u>FY 95</u>	<u>FY 96</u>
Total Recipients	1,564	1,611	1,659	1,701	1,735	1,761	1,778	1,796

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Population Research and Family Planning Activities
Obligations: Fiscal Year 1988 to Fiscal Year 1992
(dollars in millions)

	FY 88	FY 89	FY 90	FY 91	FY 92
TOTAL DHHS	\$534.6	\$544.9	\$570.1	\$618.6	\$620.9
PUBLIC HEALTH SERVICE					
<u>Office of the Assistant Secretary for Health</u>					
Office of Population Affairs					
Adolescent Family Life Program	1/	1/	1/	1/	1/
Family Planning Program	137.3	135.1	135.7	140.6	148.4 ^{2/}
Office of International Health	4/	4/	3/	3/	3/
<u>National Institutes of Health</u>					
National Institute of Child Health and Human Development	132.9	144.1	135.4	146.7	159.3
Office of the Director 5/	.3	.3	.2	.3	.3
<u>Health Resources and Services Administration</u>					
Maternal and Child Health Block Grant	6/	6/	6/	6/	6/
Bureau of Health Professions	37.5	36.5	44.4	48.2	4/
<u>Centers for Disease Control</u>	1.7	1.7	1.7	1.7	1.7
<u>Indian Health Service</u>	7/	7/	7/	7/	7/
Total PHS	309.7	317.7	317.4	337.5	309.7

DEPARTMENT OF HEALTH AND HUMAN SERVICES
(continued)

FY 88 FY 89 FY 90 FY 91 FY 92

OFFICE OF HUMAN
DEVELOPMENT SERVICES

Office of Policy and Legislation	<u>8/</u>	<u>8/</u>	<u>8/</u>	<u>8/</u>	<u>8/</u>
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HEALTH CARE FINANCING
ADMINISTRATION

Medicaid Bureau	\$224.9	\$227.2	\$252.7	\$281.1	\$311.2
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Footnotes:

- 1 The Adolescent Family Life program works to encourage teens not to become sexually active and provides health and social services to pregnant and parenting teens. Family Planning services are authorized in the program only when not available from Title X or other sources in the community.
- 2 The Administration is proposing to convert the Title X Family Planning program to a State administered program in FY 1992.
- 3 All obligations are in excess foreign currency and are not included in the PHS or DHHS totals shown.
- 4 No obligations are projected for these fiscal years.
- 5 Represents funds awarded through the NICHD for the Academic Research Enhancement Award program.
- 6 The Maternal and Child Health Block Grant expends approximately \$550 million annually for a broad range of maternal and child health services, including family planning. The proportion of this total allocated to family planning services cannot be determined through available reporting systems.
- 7 Funding for family planning services cannot be determined.
- 8 The Social Services Block Grant expends approximately \$2.7 billion annually for a broad range of social services, including family planning. The proportion of this total allocated to family planning services cannot be determined through current reporting systems.

HOMELESS					
<u>OBLIGATIONS</u>					
	<u>1988</u> <u>ACTUAL</u>	<u>1989</u> <u>ACTUAL</u>	<u>1990</u> <u>ACTUAL</u>	<u>1991</u> <u>ESTIMATE</u>	<u>1992</u> <u>ESTIMATE</u>
<u>Alcohol, Drug Abuse and</u> <u>Mental Health Administration</u>					
National Institute of Mental Health	\$ 19,148,000	\$ 30,422,000	\$ 30,341,000	\$ 30,746,000	\$ 45,880,000
National Institute on Alcohol Abuse and Alcoholism	9,200,000 ¹	4,545,000	16,378,000	16,438,000	---
MHSH Block/PATH	<u>11,489,000</u>	<u>14,128,000</u>	<u>27,813,000</u>	<u>33,057,000</u>	<u>43,116,000</u>
SUBTOTAL, ADAMHA	\$ 39,837,000	\$ 49,095,000	\$ 74,532,000	\$ 80,241,000	\$ 88,996,000
<u>Health Resources and</u> <u>Services Administration</u> ²					
<u>Bureau of Health Care</u> <u>Delivery and Assistance</u>	\$ 14,361,000	\$ 14,820,000	\$ 35,967,000	\$ 50,921,000	\$ 63,041,000
<u>Family Support</u> <u>Administration</u> ³	\$ 19,148,000	\$ 18,918,000	\$ 41,855,000	\$ 41,222,000	---
<u>Office for Human</u> <u>Development Services</u>	<u>\$ 26,089,000</u>	<u>\$ 41,923,000</u>	<u>\$ 53,453,000</u>	<u>\$ 59,857,000</u>	<u>\$ 59,857,000</u>
TOTAL, HHS	\$ 99,435,000	\$ 124,756,000	\$ 205,807,000	\$ 232,241,000	\$ 211,894,000
<u>Housing and Urban</u> <u>Development</u>	\$ 73,300,000	\$ 171,500,000	\$ 284,000,000	\$ 461,600,000	\$ 535,700,000
<u>Federal Emergency</u> <u>Management Administration</u>	\$ 114,000,000	\$ 126,000,000	\$ 130,100,000	\$ 134,000,000	\$ 100,000,000
<u>Interagency Council</u> <u>on the Homeless</u>	\$ 800,000	\$ 1,100,000	\$ 1,100,000	\$ 1,100,000	\$ 1,300,000
<u>Department of Labor</u>	\$ 9,600,000	\$ 9,400,000	\$ 11,300,000	\$ 12,700,000	---
<u>Department of Education</u>	\$ 12,000,000	\$ 11,900,000	\$ 17,300,000	\$ 17,100,000	---
<u>Department of Veterans</u> <u>Affairs</u>	\$ 13,000,000	\$ 23,700,000	\$ 30,000,000	\$ 31,500,000	\$ 33,000,000
<u>Department of Agriculture</u>	\$ 61,000,000	\$ 117,000,000	\$ 109,400,000	\$ 102,000,000	\$ 102,000,000
<u>Department of Defense</u>	<u>\$ 2,300,000</u>	<u>\$ 2,800,000</u>	<u>\$ 3,000,000</u>	<u>\$ 3,000,000</u>	<u>\$ 3,000,000</u>
	\$ 384,439,000	\$ 588,156,000	\$ 792,007,000	\$ 995,241,000	\$ 986,894,000

¹ Funds appropriated for 1987/1988; obligated in 1988.

² Includes Supplemental Appropriation of \$2.3 million for FY 1990.

³ Does not include estimated entitlements for AFDC Housing Assistance.

ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION

Homeless

Operational definitions of homelessness vary greatly from study to study, encompassing a range of variables including lack of shelter, income, social support, or affiliation with others. Despite these problems, two recent studies offer more reliable, although not definitive, estimates of the total homeless population. The National Alliance to End Homelessness has estimated that on any given night, the number of homeless individuals is 735,000. The Urban Institute concluded that the number of homeless people in the United States is between 567,000 and 600,000 on any given night.

Findings from research previously sponsored by ADAMHA suggest that the homeless population is a heterogeneous one, with multiple and diverse needs for treatment and services coordinated with appropriate housing. It is estimated that at least 35 percent of homeless individuals have chronic alcohol problems, 15-20 percent have chronic problems with other drugs, and approximately one third of the population of single homeless adults suffer from severe and disabling mental illness. Also, a substantial number of homeless individuals who are diagnosed as having a serious mental illness also have a co-occurring chronic alcohol or other drug problem.

For homeless individuals with ADM disorders, homelessness is often a chronic or recurrent situation, precipitated by a confluence of factors including the illness; resultant disabilities; and the lack of coordinated systems of care. ADAMHA is charged with assisting States and localities in meeting the ADM needs of these individuals who are often the most vulnerable and disadvantaged among the homeless population.

National Institute of Mental Health

Perhaps no group of disabled people in the United States is as impoverished and poorly served as the homeless mentally ill population. All too often, homeless mentally ill persons are disenfranchised from service providers, families, and communities. They are frequently excluded from programs designed to serve the general homeless population, and they are often screened out from receiving services designed for the long-term severely mentally ill. While homeless mentally ill persons share characteristics and needs with the homeless population generally, the added complications of mental illness sets them apart and demands special approaches.

Because the needs of this population are multiple and diverse, no single agency can address them comprehensively. NIMH uniquely contributes to this effort through research, research demonstrations, and program evaluation and technical assistance.

These projects are designed to expand the boundaries of what is known about the relationship between homelessness and mental illness and how to effectively address the needs of this population.

One-Third Of The Homeless Single Adult Population Suffer From Severe Mental Illness

The presence of a significant subgroup of mentally ill individuals among the homeless population has been an increasing source of concern. Delineating the boundaries and size of the homeless mentally ill population, however, is no simple task. Despite numerous methodological obstacles and challenges, a number of studies have attempted to discern the proportion of homeless people who have severe mental illnesses. The findings of 10 studies, supported by NIMH between 1982 and 1986, suggest that approximately one-third of the homeless single adult population suffers from severe and disabling mental illnesses, such as schizophrenia, schizoaffective disorders, and mood disorders.

Less is known about the mental health status of homeless families with children and homeless adolescents who have separated from their families. Overall, families represent approximately 36 percent of the homeless population, and children in these families are estimated to comprise 21 percent of the total homeless population (U.S. Conference of Mayors, 1989). The U.S. General Accounting Office reported in 1989 that on any given night about 68,000 children under the age of 16 are homeless and another 186,000 are living in shared housing. These estimates do not include runaway children and youth.

In its 1989 report, Research on Children and Adolescents with Mental, Behavioral, and Developmental Disorders, the Institute of Medicine (IOM) includes homelessness as one of the factors that place children at risk for emotional disturbance. Many other risk factors for emotional disturbance are common among homeless children, including inadequate prenatal care, chronic physical illness, cognitive impairments, poverty, abuse or neglect, disturbed family relationships, parental mental illness, and exposure to toxic chemicals or drugs. In a study of homeless families living in Massachusetts family shelters, Bassuk and her colleagues found that a majority of the children were suffering developmental delays, severe anxiety and depression, and learning difficulties. Approximately half of the sheltered homeless children required psychiatric evaluation and referral.

The Homeless Mentally Ill Are A Multi-Need Population

Severe mental illness places one at a greater risk of homelessness. Severely mentally ill people frequently have a marginal economic status. Disability income or sporadic employment may constitute their only source of support, making it extremely difficult for a severely mentally ill person to secure and retain affordable housing. Periodic hospitalization may add to the difficulty of keeping one's housing. Because a

substantial proportion of severely mentally ill persons do not hold jobs, they are more likely to be affected by levels of public assistance than by reductions in employment opportunities. Supplemental Security Income (SSI) benefits support approximately one-half of persons with severe, disabling mental illness. In many cities it is impossible to find housing that costs less than an SSI monthly payment.

Severely mentally ill homeless persons are often unable to obtain needed services. In addition to the problems all homeless persons face in applying for housing, benefits, and services, those who are also mentally ill often confront additional obstacles. They may be especially vulnerable to stress and unable to cope during a time of crisis. People with severe mental illness tend to have fewer family and social supports than people without mental illness, and the paucity of such supports probably contributes to homelessness. A NIMH-supported study of the homeless population in Los Angeles found that homeless mentally ill persons had even more impoverished social supports than other homeless persons; those who were mentally ill and homeless were less likely to be in contact with family or friends and more likely to have poor relations with their families.

Between 1982 and 1986, NIMH funded 10 descriptive research studies on the homeless mentally ill population. These studies were designed to assess the demographics, mental health status, and service needs of homeless individuals. Some of the major findings that have emerged include the following:

- o A sizeable number of homeless mentally ill people have had involvement with the criminal justice system, although arrests were often associated with relatively minor offenses.
- o Many homeless mentally ill persons have never received mental health treatment, and many homeless mentally ill persons formerly in treatment are not disabled by their mental illness.
- o A significant proportion of the homeless mentally ill population is interested in receiving help, but their perceptions of their own service needs often differ from the perceptions of service providers. Homeless mentally ill persons place a high priority on meeting their basic subsistence needs, before addressing their mental health needs, whereas mental health professionals often place a higher priority on providing traditional mental health treatment.

One of the major conclusions that can be drawn from these findings is the need for comprehensive systems of care that can provide for homeless mentally ill persons' housing, health, mental health, and other social welfare needs.

ACCOMPLISHMENTS

NIMH is involved in a number of historic interdepartmental initiatives designed to assist the homeless mentally ill population. Perhaps of most importance, are the recent HUD/HHS Memorandum of Understanding and the Task Force on Homelessness and Severe Mental Illness.

Memorandum of Understanding

One of the three target groups under the January 1990 Memorandum of Understanding (MOU) between HHS and HUD (intended to improve coordination of housing and services to the homeless) is the homeless mentally ill population. NIMH has been working closely with HUD to sponsor a number of joint activities including: pilot projects in communities, policy review and development, and research and evaluation.

The MOU workgroup on the homeless mentally ill population has four subcommittees on technical assistance, training, mentally ill people living in public housing, and housing mentally ill people with co-occurring substance abuse disorders. The subcommittees are developing and implementing Federal activities that will facilitate the coordinated provision of integrated housing and mental health services to the homeless population at the local level, including:

- o Training sessions to familiarize HUD staff with substantive and program issues pertaining to the homeless mentally ill, and to familiarize HHS staff with relevant HUD programs and housing issues.
- o Joint NIMH and HUD funding of a competitive 4-year research grant to examine the costs of developing housing for severely mentally ill persons.
- o Development of technical assistance materials for regional offices to develop similar MOUs supporting the coordination of housing and services.
- o Development of a blueprint for cooperative agreements between local public housing authorities and local mental health authorities focused on the mentally ill.
- o Consultation between NIMH and HUD on program announcements, application reviews, legislative proposals, and other policy matters concerning the integration of housing and mental health services.

Task Force on Homelessness and Severe Mental Illness

In May 1990, Secretary Sullivan established an interdepartmental Task Force on Homelessness and Severe Mental Illness. This 18-month Task Force has a broad mandate to examine the systemic problems that make severely mentally ill people particularly vulnerable to homelessness. The Task Force is chaired by the

Director of NIMH, and it comprises representatives of the Federal Interagency Council on the Homeless. An outside Advisory Group will consist of the Director, NIMH; individuals from State and local governments; non-profit providers and research organizations; members of the private sector who either finance, manage, conduct research, or provide services to the homeless mentally ill population; and consumers/family members. The Task Force will review research findings and solicit expert advice on:

- o Effective methods for providing treatment and coordination of appropriate services to severely mentally ill persons, particularly those who are homeless;
- o The prevalence, causes, and treatment of major mental illnesses among the homeless population;
- o Approaches to preventing homelessness among severely mentally ill persons; and
- o Factors that impede access of severely mentally ill persons, particularly those who are homeless or at high risk of homelessness, to housing, mental health, income support, and human service programs.

The Task Force will make recommendations to the Federal Interagency Council on the Homeless so that the Executive Branch can outline a course of action that will enable States and localities to better meet the housing, treatment and support needs of severely mentally ill and homeless mentally ill persons.

CURRENT ACTIVITIES

Research and Research Demonstration Efforts

The NIMH Office of Programs for the Homeless Mentally Ill coordinates an extensive research effort to improve care and treatment of homeless severely mentally ill people. The Office administers an Institute-wide program of research on homelessness and mental illness, and manages the McKinney Research Demonstration Program. The Office also worked collaboratively with ADAMHA on the McKinney Mental Health Services for the Homeless (MHSH) Block Grant program, and will be instrumental in responding to the newly authorized Projects for Assistance in Transition from Homelessness (PATH) program; provides technical assistance to potential grant applicants; and disseminates research findings to a broad audience of service providers, policy makers, and other researchers.

In FY 1989 NIMH awarded ten research and research demonstration grants totalling \$3.1 million in response to a program announcement, "Research and Research Demonstrations on Homeless Severely Mentally Ill Adults and Homeless Families with Children Who Are at Risk of Severe Emotional Disturbance". NIMH expects these grants to accelerate the development of methodologically rigorous knowledge that can contribute to more effective delivery

of mental health services to homeless persons, reduce homelessness among those who are mentally ill, and reduce mental illness among those who are homeless. In FY 1990, NIMH funded the continuation of these grants, and made eight new awards, for a total of over \$5.8 million. Descriptions of the eight grants are as follow:

- o **Service Use and Homelessness in Chronic Mental Illness** (Columbia University) expands and adds women to an on-going NIMH-funded study of homelessness among men with schizophrenia. Two hundred persons will be selected from shelters in New York City and matched to 200 domiciled individuals, chosen from among referrals for psychiatric aftercare. Researchers will examine such factors as family disorganization in childhood and conjugal settings, the illness itself, and prior service use.
- o **Gender Differences Among Homeless Persons** (University of Chicago) is a predoctoral fellowship award that will examine how the complex relationship between poverty and homelessness differs by gender and identify the distinctive service needs of men and women. This involves a secondary analysis of a data set comprised of 535 impoverished homeless and domiciled individuals. Gender differences in factors that have relevance to homelessness will be explored, including mental illness, social support networks, employment and welfare experience.
- o **The Cost of Developing Housing for Mentally Ill Persons** (Johns Hopkins University) will collect the first systematic data on total housing development costs for chronically mentally ill people. This grant will develop a conceptual framework and analytic strategy, building on standard approaches to housing cost analysis, and apply it to a sample of 1,200 housing units for chronically mentally ill persons developed for the Robert Wood Johnson Foundation Program for the Chronically Mentally Ill.
- o **Emotional Development and Cognition in Homeless Children** (Albert Einstein College of Medicine) is a 2-year, cross-sectional study of 150 homeless mothers and children and two comparison groups of 150 low-income, precariously housed mothers and children. This research will examine the specific effects (medical, cognitive, and psychological) of homelessness on children.
- o **Dynamics of Homelessness and Mental Illness in Families** (New York University) is a longitudinal research project aimed at clarifying the dynamic relationship between homelessness and mental health among mothers and children. Researchers will examine the degree to which mental illness leads to homelessness; the degree to which homelessness may lead to mental illness in adults and emotional disturbance, health problems, and school problems in children; and the extent to

which mental illness hinders the resettlement of those who are homeless. The project will build on a data set drawn from interviews with 701 homeless families and records of 524 families from public assistance case loads.

- o **Follow-up Study of Homeless Adult Shelter Residents (New York State Psychiatric Institute)** will perform interviews with representative samples of 304 women and 848 men previously interviewed in 1987 as residents of the New York City shelter system. Particular focus will be placed on housing status and other quality of life measures to understand the relationship of homelessness to individual outcomes.
- o **Cost-Effectiveness of Nine Residential Crisis Modalities (Texas Department of Mental Health)** will provide non-traditional residential psychiatric crisis care alternatives to 240 persons and expand the knowledge base about relative costs, efficacy, and consumer satisfaction. The population to be studied are individuals with severe and persistent mental illness who are either homeless, have frequent contact with the law, or are high users of emergency services. Experimental interventions include two levels of hospitalization, two levels of community-based residential care based on location, and two levels of community-based residential care based on provider of services.
- o **Effectiveness of Case Management for Homeless Adolescents (University of Washington)** will evaluate the effectiveness of case management services for homeless adolescents. This study will examine the prevalence of mental disturbance among homeless adolescents, develop an adolescent-centered intensive case management program for these individuals and compare the relative effectiveness of this model with the current services system in Seattle.

In FY 1991 NIMH will revise and reissue this announcement to encourage studies that further examine the special needs of homeless severely mentally ill people. The announcement will encourage research on: 1) understudied homeless sub-populations; 2) co-occurrence of severe mental illness with alcohol and/or other drug disorders; 3) the relationship between mental illness, HIV infection, and homelessness; 4) the prevalence of recent history of physical and/or sexual abuse among homeless children or adolescents, and studies of such abuse as a risk factor; and 5) service needs of homeless severely mentally ill persons dwelling in public transportation or street dwellings; and 6) approaches to linking housing and services.

McKinney Community Mental Health Demonstration Projects for the Homeless Chronically Mentally Ill

Since May, 1988, authorized by Section 612 of the Stewart B. McKinney Homeless Assistance Act, as amended, NIMH has awarded nine demonstration projects for homeless severely mentally ill adults and three projects for homeless children and adolescents who are at high risk of emotional disturbance.

The projects for homeless mentally ill adults are intended to support and evaluate comprehensive, community-based mental health service systems. These projects are designed to provide outreach, case management, mental health treatment, supportive housing, and coordination of these services in a comprehensive system of care. Optional services include day programs providing training in daily living skills, rehabilitation and vocational assessment, consumer-run self-help programs, and training of professional and volunteer staff. The projects for homeless children and adolescents are intended to develop discrete service demonstrations to identify the mental health and support needs of this population. Examples of the projects include:

- o In Nashville, a four part effort, including:
 - 1) client-oriented case management, 2) a mobile psychiatric outreach team, 3) housing, and 4) outreach services to the underserved Black population. The mobile team brings psychiatric and medical services directly to homeless mentally ill individuals too fearful to come to traditional settings. Over 800 individuals have been contacted. The project has provided some service to 250 individuals and enrolled 136 into the program on an on-going basis. Permanent housing has been arranged for 115 persons.
- o In Cleveland, the "Money and Mailboxes" demonstration project is a non-traditional service approach designed to attract and promote public-private partnerships for the development of low-income, permanent housing. The Ohio Department of Mental Health has made \$1 million for capital construction available through contractual agreements that leverage guaranteed, low-rent housing for severely mentally ill homeless persons. Over 1800 individuals have received outreach services and the active caseload is around 160. Permanent housing placements have been found for 120 homeless mentally ill individuals, and 142 persons have been placed in efficiencies or single room occupancy dwellings based on their personal preferences.
- o The New York City project focuses on homeless mentally ill women in shelters. Women are identified and screened by psychiatric teams for severe mental illness and referred to the program for case management, mental health treatment and placement in supportive housing. The primary goal is placement and maintenance in supportive housing. The project has served approximately 135 individuals. Services

will be provided to 250 disabled persons over the course of the grant.

- o The Maine Department of Mental Health is collaborating with a coalition of service providers in Portland to operate a mental health treatment and support services program for children and adolescents with severe emotional disturbance who are homeless or at imminent risk of becoming homeless. A multi-disciplinary mobile outreach team conducts mental health and substance abuse screening and needs assessments in settings where homeless, severely emotionally disturbed children and adolescents are found.

An integral component of the demonstration program is a national evaluation. In addition to the national evaluation effort, each of the nine adult projects has a local evaluator who is responsible for conducting both an implementation and outcome assessment for the projects. During the third year of the projects, at least 15 percent of the grant funds are to be spent on evaluation activities.

In FY 1990, NIMH made six new three-year research demonstration grant awards focused on homeless severely mentally ill persons. These grants support the provision of comprehensive community mental health services coordinated with housing services, and study the effectiveness of one or more of these service components. Under the recent HHS/HUD Memorandum of Understanding, HUD agreed to give preferences, to the extent possible, in its rating and award criteria to NIMH applicants who concurrently applied for HUD funding in FY 1990.

These grants were:

- o **Apartments vs. Evolving Consumer Households for Homeless Mentally Ill Persons** (Harvard Medical School) is designed to demonstrate the effects of two housing models for homeless mentally ill persons currently living in transitional shelters: independent living and specially designed group homes. The group homes will begin with 24-hour program staff but will gradually increase client participation in all aspects of household management until they become autonomous, consumer-run homes. Consumers experienced in self-help activities will provide on-site consultation and training.
- o **Transitional vs. Permanent Housing for Homeless Mentally Ill Persons** (Hamilton County Mental Health Board) compares the efficacy of transitional vs. permanent housing for homeless mentally ill persons in Cincinnati. Individuals in both transitional and permanent housing arrangements will receive on-site case management, psychiatric treatment, and training in skills needed to live in permanent housing. Persons in transitional housing will move to permanent housing, and both groups will be linked with community services.

- o **Client-Focused Housing Support Services for Homeless Persons (San Diego State University)** evaluates the effectiveness of providing comprehensive supportive services coordinated with independent housing alternatives for severely mentally ill homeless adults. University researchers will work with San Diego County Mental Health Services and the San Diego City Housing Commission, to provide up to 200 HUD Section 8 certificates and vouchers. Emphasis will be on individual choice in both the selection of housing options and supportive services. Researchers hypothesize that persons in the experimental program will show decreased levels of psychopathology, increased housing stability, and an improved quality of life compared to others receiving traditional case management.
- o **Baltimore Program for Homeless Mentally Ill Persons (University of Maryland)** evaluates the effectiveness of an assertive community treatment (ACT) program adapted to serve homeless mentally ill persons. Researchers expect the ACT program to increase access to health and mental health services and housing, enhance functional status, and improve the quality of life for homeless mentally ill persons.
- o **Housing Mentally Ill Street People: A Rehabilitation Approach (New York State Office of Mental Health)** is a joint effort of New York State, the New York City Health and Hospitals Corporation, and the Center for Psychiatric Rehabilitation at Boston University. It will emphasize on-site psychiatric rehabilitation in stable, long-term housing that, to the degree possible, reflects an individual's choice. This intervention will be compared to a control group that receives "normal" community services for homeless mentally ill individuals.
- o **Critical Time Intervention for Homeless Mentally Ill Men (New York Presbyterian Hospital)** studies the effectiveness of providing continuous mental health services for men with schizophrenia leaving a large New York City men's shelter. Men in the experimental group will receive specialized support called Critical Time Intervention, which includes training in community living skills after placement in housing and team-managed coordination of linkage to community services. The control group will receive outreach and housing placement services offered within the shelter. The researchers believe the experimental intervention will prevent future episodes of homelessness by stabilizing the men during the critical transition period from homelessness to permanent housing.

Mental Health Services for the Homeless Block Grant/Projects To Aid The Transition From Homelessness (PATH)

The MHSB Block Grant Program was authorized under Section 611 of the Stewart B. McKinney Homeless Assistance Act. The block grant

program provided funds for six essential services: outreach, community mental health services, referral for hospital and appropriate primary health and substance abuse services, training for service providers, case management services, and supportive and supervisory services in residential settings.

As a condition of receipt of MSHS funds, States were required to submit annual reports describing the activities undertaken as part of this program. In addition to the annual reports, in February, 1990 the National Association of State Mental Health Program Directors (NASMHPD) surveyed 49 States to determine an estimate of the number of homeless mentally ill individuals served under the MSHS Block Grant Program since its inception. NASMHPD estimated that approximately 69,267 individuals received some form of mental health services. However, estimates were not completely comparable across States.

The MSHS Block Grant has provided much needed funds for the homeless mentally ill population. For many of the States, these are the only specialized monies designated to provide essential services to this vulnerable segment of the homeless population; without this program, there would be no services available. For other States, these funds support programs and services that help fill gaps in the already existing service system; funds in this case are used to expand the number and range of services that are appropriate to persons who are homeless and mentally ill. The program has increased awareness of service needs of this population at Federal, State, and local levels.

Last year, the reauthorization of the McKinney Act included the new "Projects to Aid the Transition from Homelessness" (PATH) legislation. PATH attempts to build upon and expand the current MSHS Block Grant. The new formula grant program funds comprehensive services for homeless severely mentally ill individuals. The new program expands the focus on co-occurring (mental health and substance abuse) disorders and encourages closer integration of housing, treatment, and support services. PATH retains the requirement that States provide non-Federal matching funds of \$1 for each \$3 of Federal funds.

Technical Assistance Efforts

NIMH has initiated a broad array of knowledge dissemination and technical assistance projects. On-site and telephone technical assistance to the demonstration projects is provided by the National Resource Center on Homelessness and Mental Illness. The Center assists grantees in designing, implementing, and maintaining feasible, high quality interventions, and works to improve service delivery to homeless mentally ill persons by assisting other Federal, State, and local programs.

During its first 22 months of operation the Center answered over 4,350 requests for information and assistance from a variety of service providers, researchers and educators, students, policy makers, and national organizations. The center has an 800

telephone number that provides easy access for callers [800-444-7415], who include indigent persons and non-profit shelter and mental health service providers. The Center is currently working with the Federal Interagency Council on the Homeless to develop a public education document on outreach to the homeless street population.

NIMH is also supporting numerous program focused on research development in the area of homelessness and mental illness. One such effort is a 2-phase technical assistance program for minority investigators to stimulate research and research demonstration projects on severely mentally ill homeless populations. NIMH and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) are co-sponsoring a national workshop on homeless families with children to be held in the winter of 1991. The invitational conference of leading researchers will establish an agenda and set of priorities for research concerning the needs and problems of homeless families with children. Special emphasis will be given to the relationship between homelessness and alcohol, drug, and mental disorders.

National Institute on Alcohol Abuse and Alcoholism

While studies of the homeless individual with alcohol problems conducted in the early 1970s dealt with chronic public inebriates or skid row alcoholics, today's homeless population is much more diverse. It now includes women, families with children, adolescents, minorities, the seriously mentally ill, and younger, single adults who may abuse other drugs as well as alcohol. In addition to the multiple problems of homelessness and the abuse of alcohol and other drugs, the homeless person also tends to suffer from poverty, malnutrition, unemployment, physical disabilities, and mental illness.

The multiple causes of homelessness tend to be interrelated. They can be identified at both individual and societal levels. On an individual level, persons who have a problem with alcohol or other drugs, and who are in marginal economic circumstances, are at especially high risk for homelessness. Risk increases when use of alcohol and other drugs leads to the loss of a job, an eviction notice, or an incidence of domestic violence. Moreover, displacement to a hotel, shelter, or the streets can exacerbate the problem; homeless individuals may turn to drink or other drugs to numb their senses from the difficulties encountered in these settings.

ACCOMPLISHMENTS AND CURRENT ACTIVITIES

Since 1984, The National Institute on Alcohol and Alcohol Abuse (NIAAA) has supported research, technical assistance and information dissemination regarding homelessness and alcohol problems. The present program includes large scale, multi-site research demonstration projects; a research grant program dealing with prevention, identification, treatment and rehabilitation of homeless people with alcohol problems; collaborative efforts with other Federal agencies with programs targeted on the homeless population; and a considerable number of research and technical assistance publications.

Research Demonstration Programs

In consultation with the National Institute on Drug Abuse (NIDA), NIAAA currently administers two research demonstration grant programs focused on homeless persons with alcohol and other drug problems. These research demonstration programs were authorized under Section 613 of the Stewart B. McKinney Homeless Assistance Act (P.L. 100-77). They are: the Community Demonstration Grant Projects for Alcohol and Other Drug Abuse Treatment of Homeless Individuals, and the Cooperative Agreement Research Demonstration Program for Alcohol and Other Drug Abuse Treatment of Homeless Individuals.

Community Demonstration Grant Projects

This program was funded in May of 1988. The mission of this research demonstration program is to provide and evaluate a variety of approaches to community-based alcohol and other drug treatment and rehabilitation services for individuals with alcohol or other drug problems who are homeless or at risk of becoming homeless. Grant awards were made on a competitive basis to nine programs in eight major cities: Anchorage, Boston, Los Angeles, Louisville, Minneapolis, New York City, Oakland, and Philadelphia (two projects).

A wide variety of treatment approaches are represented in the nine projects including outreach and engagement, intensive case management, supportive housing arrangements, and systems level interventions. These services are provided to a number of subgroups of the homeless population: traditional skid row alcoholics, women with children, American Indians and Alaskan Natives, and persons experiencing both a serious mental illness and alcohol or other drug problems.

A high priority has been assigned to evaluation of project effectiveness in this first generation of demonstration projects. Projects are required to conduct client-level process and, where possible, outcome evaluations of their programs. Several projects are evaluating program impact on the network of services for homeless persons. Projects are also required to participate in a national evaluation of the demonstration project.

A final report on this demonstration program will be available in early 1992. This report will include detailed case studies on each of the nine sites that will allow local communities to develop treatment programs based on what was learned from the demonstration project. The report will also include results on the outcome of the different treatment models which will be used by service providers to refine their treatment interventions making them more effective for this population. Researchers will also be interested in these results which will generate hypotheses for future research studies. Finally, information on the characteristics of this population, the effectiveness of these interventions, and the implementation of the programs will help to shape future public policy in the area of alcohol and other drug problems in homeless individuals.

Cooperative Agreement Research Demonstration Program

This program received \$16.4 million in funding for fiscal year 1990. These funds have been used to support fourteen research demonstration projects described as follows:

- o Substance Abuse Treatment Programs for Homeless Persons (Lovelace Medical Foundation, Albuquerque) is collaborating with St. Martin's Hospitality Center and Health Care for the Homeless to evaluate the effectiveness of transitional housing services and three levels of structured assistance. The project is comparing case management-facilitated recovery services in supervised housing with self-initiated services in supervised and unsupervised, motel-based housing. The project is providing services to approximately 500 homeless men and women drawn from Hispanic, non-Hispanic White and Native American populations.
- o Comparative Substance Abuse Treatments for the Homeless (University of Alabama at Birmingham) along with Birmingham Health Care for the Homeless Coalition is comparing the effectiveness of a "usual care" intervention with an intensive outpatient program. The project provides services for about 150 homeless men and women with alcohol or drug abuse problems.
- o Demonstration of Case Management and Supportive Housing (University of Chicago) is working with the University of Illinois (Champaign-Urbana) in collaboration with Travelers and Immigrants Aid of Chicago to compare intensive case management, intensive case management with supportive housing, and a control group receiving "usual services." This project provides services to about 440 homeless men and women.
- o Intensive Case Management for Homeless Substance Abusers (University of Denver) is examining the effectiveness of an Intensive Case Management program in collaboration with Arapahoe House. This project provides outreach, drop-in, case management and shelter services to 350 homeless men and women in the Denver metropolitan area.
- o Case Managed Residential Care for Homeless Addicts (Northwestern University) is collaborating with the Hines VA Hospital to evaluate a case managed residential care program for homeless veterans with alcohol and other drug problems. The study involves approximately 270 homeless male veterans and includes an economic analysis of whether the costs of providing the experimental intervention are offset by reductions in the use of other health and mental health services.
- o Evaluation of Treatment Options for the Dually Diagnosed (RAND Corporation) is collaborating with three Los Angeles treatment facilities in evaluating the effectiveness of residential and non-residential treatment programs for individuals with co-occurring psychiatric and alcohol or other drug dependence

diagnoses. This project provides services for 280 homeless men and women.

- **Homelessness, Substance Abuse: An Investigation of Two Interventions** (University of Medicine and Dentistry of New Jersey) is working with the City of Newark and the Archbishop Bolan Rehabilitation and Training Center to study the effects of case management and specialized pre-vocational training and job placement. This project serves 300 Black and Hispanic men who have completed a period of detoxification and inpatient rehabilitation. All of the study participants receive alcohol and drug-free transitional housing.
- **Research on Services for Homeless Substance Abusers** (Yale University) is collaborating with Hill Health Center and Grant Street Shelter to examine the impact of adding a new short-term residential shelter and day treatment program to existing services for homeless men with cocaine abuse problems. This project serves approximately 350 homeless men.
- **New Orleans Homeless Substance Abuse Project** (Tulane University) is working with the Center for Supervised Residential Services of Metairie to examine the effectiveness of transitional housing and an extended care/independent living program for homeless single men and women, husband-wife pairs, and homeless women with children. This project involves about 1,500 clients.
- **Assessing Treatments for Homeless Poly-Addicted Men** (Temple University) is working with the Diagnostic and Rehabilitation Center in Philadelphia to investigate the effectiveness of shelter services and case management with 700 homeless, poly-addicted men.
- **Substance Abusing Homeless Families, Breaking the Cycle** (Washington University) is collaborating with Grace Hill Neighborhood Services and the Salvation Army Family Shelter in focusing on the treatment needs of homeless women and children. The project is comparing the effects of three forms of extended treatment: alcohol and drug-free supervised housing with a "holistic" approach to treatment of women with children, long-term child development services and family therapy, and 12-month case management of the family. This project serves approximately 240 women and their children.

- o Intensive Case Management for Chronic Public Inebriates (University of Washington at Seattle) is working with the King County Division of Alcoholism and Substance Abuse to examine the effects of long-term intensive case management with chronic public inebriates. This project provides services to about 300 homeless men and women who have been selected from among the most frequent users of the King County Detoxification Center.
- o Southern Arizona Alcohol/Drug Program for the Homeless (Amity, Inc., Tucson) is collaborating with the University of Arizona College of Medicine to compare a new outpatient treatment program with a modified therapeutic community. This project provides services to 432 homeless men with alcohol and other drug problems.
- o Washington Homeless Dual Diagnosis Project (Dartmouth Medical School) is collaborating Howard University and Community Connections in Washington, D.C. to evaluate two independent models of intensive case management services for homeless men and women with co-occurring disorders of alcohol and other drug problems and serious mental illness. This project provides treatment services for approximately 200 individuals, with a particular emphasis on the treatment of women and minorities.

The implementation of service interventions coupled with the evaluation requirements of this research demonstration program has necessitated strong working collaborations between service providers who can offer alcohol and other drug rehabilitation services to homeless persons, and expert researchers in the areas of homelessness, alcohol and other drug treatments, and evaluation. Evaluation research is emphasized in the cooperative agreements. The national evaluation is developing a centralized client-level data base consisting of standardized measures of client demographic characteristics, service utilization, alcohol consumption, residential stability, and employment status. At the individual project level, research teams will address a variety of implementation and outcome questions.

Research Studies

In addition to the McKinney Research Demonstration Program, the Institute also supports a number of research grants. These include the following:

- o Patterns of Alcoholism in Subsamples of the Homeless (Washington University). This is an epidemiologic study of alcoholism and other psychiatric disorders in the St. Louis homeless population.

- o **Treatment of Dual Diagnosis and Homelessness** (Dartmouth College). The long-term objective of this study is to develop appropriate and effective treatment for people with co-occurring disorders of alcohol and other drug abuse and chronic mental illness.
- o **Alcoholism and Homelessness: An Empirical Analysis** (University of Wisconsin). This research examines the relationship between alcoholism and homelessness including: 1) the degree to which alcohol can be linked to homelessness; 2) the factors that condition whether or not alcohol use results in homelessness; and 3) the patterns of homelessness in individuals who vary in the severity of their drinking patterns.
- o **Risk Factors for Homelessness in Alcoholics: A Longitudinal Study** (Johns Hopkins University). The goals of this study are: 1) to identify the differences in the characteristics of homeless and domiciled alcoholics which are risk factors for homelessness in alcoholics; 2) to test the predictive value of the identified risk factors of homelessness through longitudinal study of domiciled alcoholics; and 3) to propose strategies for preventing homelessness among high risk indigent domiciled alcoholics.

Information Dissemination/Technical Assistance Activities

NIAAA disseminates a wide range of information including research reports and other publications on alcohol and other drug problems and homelessness through a variety of sources. One main method for doing this is a periodic mailing to 2,000 individuals and organizations. Other methods of dissemination include: government reports; publication of articles in both lay and professional journals; and presentations at research conferences and meetings dealing with policy formulation and provision of services to the homeless population.

Specifically, in the last year the Institute has published a number of technical assistance papers and manuals directed to service providers, policy makers, and the research community. Among these is included A Guide to Housing For Low-Income People Recovering From Alcohol and Drug Problems, a technical assistance paper designed to help service providers and housing developers work together in developing specialized housing for formerly homeless people who are recovering from alcohol and other drug problems. Another, Application of Case Management in Alcohol and Drug Dependence: Matching Techniques and Populations, is a review of case management as a treatment intervention for homeless individuals with alcohol and other drug problems. NIAAA is currently working on two manuals to assist service providers who work with the homeless population. One of these will look at alcohol and other drug problems as they relate to job training and employment issues. The other is directed toward the front-line shelter and soup kitchen worker and discusses how to deal

with individuals who have an alcohol or other drug problem in a general service setting.

PLANS FOR FY 1991

In FY 1991, NIAAA plans a number of research activities that assess the efficacy of service interventions for homeless persons with alcohol and other drug problems. The Institute is exploring collaborative research demonstration projects with other Federal agencies and private non-profit foundations on issues such as the prevalence of alcohol and other drug abuse among homeless individuals, services for homeless families, and innovative housing alternatives. As part of the information dissemination strategy, NIAAA is sponsoring a national conference in conjunction with NIDA and the Interagency Council on the Homeless focused on effective housing models for homeless people with alcohol and other drug problems. This conference will include officials from the HUD, treatment and recovery service providers, public housing officials, and private housing developers.

Additional activities include encouraging more coordination between NIAAA research demonstration programs and researchers interested in evaluating similar treatment interventions in more controlled settings. These demonstration programs will provide researchers with excellent opportunities for more basic treatment outcome-oriented studies of services for homeless persons with alcohol and other drug problems, as well as inform service providers and policy makers regarding the most effective treatment interventions to meet the multiple needs of this population.

HEALTH CARE FOR THE HOMELESS

HEALTH RESOURCES AND SERVICES ADMINISTRATION
Bureau of Health Care Delivery and Assistance

Under the Stewart B. McKinney Homeless Assistance Act of 1987, the Bureau made awards to community-based organizations and coalitions to provide primary health care, substance abuse, mental health, and case management services to homeless individuals. As a means of improving access to community services, all Health Care for the Homeless Programs (HCHP) have developed linkages, i.e., community coalitions (where none existed) which have included both public and voluntary agencies and programs that offer such services as meals, shelter, social services, employment training, and job placement.

The 109 HCHP projects represent both rural communities and large metropolitan areas and include organizations such as local Health Departments, Robert Wood Johnson/PEW foundation demonstration projects, community and migrant health centers, and substance abuse and mental health programs. Projects are supported in 103 cities in 43 States, the District of Columbia and the Commonwealth of Puerto Rico. It is estimated that the primary health and substance abuse services provided by the 109 grantees will benefit more than 350,000 individuals during 1991. Each of these has been actively involved in developing local coalitions composed of health care providers and social services agencies in an effort to maximize community resources for the provision of related services such as food and clothing, shelter, employment training, and job placement.

Bureau of Health Professions

In FY 1990, one Nursing Special Project grant in the amount of \$199,868 is focused specifically on providing health care to the homeless.

FAMILY SUPPORT ADMINISTRATION

Homeless Assistance

The McKinney Act, as amended, provides funds under the Emergency Community Services, Homeless Grant Program (EHP) to assist families and individuals who are homeless or are about to become homeless. The EHP funds may be used to: (1) expand comprehensive services to homeless individuals to provide follow-up and long term services to enable the homeless to move out of poverty; (2) provide assistance in meeting social and maintenance services for homeless individuals; (3) promote private sector and other assistance to the homeless; and (4) after October 1, 1988, use up to 25% of funds annually to provide assistance under certain conditions to an individual who has received a notice of foreclosure, eviction, or termination of utility services, in order to prevent them from becoming homeless.

Assistance to homeless families is available through programs which provide benefits under the Aid to Families with Dependent Children (AFDC) and Emergency Assistance (EA) programs. Financial assistance may be in the form of cash or in-kind benefits and can include rent, utilities, and other shelter-related items. The AFDC and EA programs are administered by State and local agencies under plans developed by each State which determines need, payment amount, and scope of coverage. These programs are jointly funded by Federal, State and, in some cases, local governments. Since no data are available on the number of families who are both needy and homeless, estimates of the benefits paid for homeless assistance are based on reported State expenditures for temporary housing assistance.

OFFICE OF HUMAN DEVELOPMENT SERVICES

Homelessness

- The Runaway and Homeless Youth Program provides financial assistance to establish or strengthen community-based centers designed to address the needs of runaway and homeless youth and their families. Funding for fiscal year 1991 will support approximately 355 runaway and homeless youth shelters, the national toll-free runaway youth hotline, training and technical assistance, research and demonstration projects, and networking grants to support mutual problem-solving cooperation among shelters. Approximately one-third of the youth seeking overnight services identified themselves as being homeless.
- The Transitional Living Program for Homeless Youth, funded for the first time in fiscal year 1990, addresses the shelter and service needs of homeless youth through financial support and technical assistance to public and private non-profit entities. Grants are used to (1) develop or strengthen community-based programs which assist homeless youth in making a smooth transition to a productive adulthood and social self-sufficiency, and (2) provide technical assistance to enhance the capacity of grantees serving youth in transition to acquire and maintain resources and to establish community service linkages to benefit program participants. In fiscal year 1990, 50 grants were awarded each for 15 months with continuation funding planned in 1992. In 1991, approximately 25-30 additional new grants will be funded for 15 months each.
- The Drug Education and Prevention Program for Runaway and Homeless Youth authorizes grants to public and private non-profit agencies, organizations and institutions for research, demonstration and service projects. Priority for funding is given to agencies experienced in providing services to runaway and homeless youth. Grants are used to support counseling, community education, training, research, local program service coordination, and other activities concerned with preventing drug abuse among runaway and homeless youth. During fiscal year 1990, 164 competitive grants were awarded to improve or expand existing services, develop information and service networks in rural and minimal service areas, develop innovative model programs, and to serve Native American youth. In addition, a prototype drug education training program will be developed under contract for technical assistance to runaway and homeless youth service providers.

Homelessness, page 2

In fiscal years 1991 and 1992, annual amounts of \$14,786,000 will continue to support projects for comprehensive service delivery and resource development for runaway and homeless youth and their families, training for youth service providers, and research, technical assistance, monitoring and evaluation of grantee activities.

- Five demonstration projects for Comprehensive Early Intervention Strategies to Prevent Homelessness Among At-Risk Families were funded in fiscal year 1990 under the Office of Human Development Coordinated Discretionary Funds Program. These projects are designed to address problems of low-income families who either are, or at risk of becoming, homeless to help enable them to obtain and sustain social and economic self-sufficiency. These projects are expected to be continued in the next two years.
- In addition, States may use Social Services Block Grant (SSBG) funds, Child Welfare State Grant funds, and others for services to the homeless. However, States are not required to report the amounts of funds used for such service.

HUNTINGTON'S DISEASE
Obligations

	1988 <u>Actual</u>	1989 <u>Actual</u>	1990 <u>Actual</u>	1991 <u>Estimate</u>	1992 <u>Estimate</u>
<u>National Institutes</u>					
<u>of Health:</u>					
National Institute					
of Neurological					
Disorders and					
Stroke.....	\$23,907,000	\$29,612,000	\$33,124,000	\$41,780,000	\$44,704,000
National Institute					
on Aging.....	---	959,000	974,000	1,008,000	1,043,000
Total, NIH....	23,907,000	30,571,000	34,098,000	42,788,000	45,747,000

NATIONAL INSTITUTES OF HEALTH

National Institute of Neurological Disorders and Stroke

HUNTINGTON'S DISEASE

Huntington's disease (HD) is a progressive, neurodegenerative disorder that robs patients of their motor control, intellect, and emotional well-being. An inherited disease, HD challenges family members as well, taxing their emotional and financial resources. HD causes people at risk and their families to spend much of their lives anxiously watching for unobtrusive signs--facial tics, mood changes, stumbling, or unusual forgetfulness--that may signal the onset of this complex, fatal disorder.

Some 25,000 people in the United States have Huntington's disease, and five times as many people are at risk for it. The effects of the disease are grim. As the disease progresses, the brain cell death that is the basis of its symptoms continues. As symptoms worsen, patients develop slurred speech, writhing movements known as chorea, and later, dementia. Eventually, HD patients have difficulty communicating and are confined to a wheelchair or bed. Death usually occurs 10 to 20 years after the first symptoms appear, and often is caused by factors indirectly related to the disease, such as choking, head trauma, or infection.

HD is a dominant hereditary disorder. Thus, each child of an affected parent has a 50-50 chance of inheriting the gene and developing the disease. The disease usually strikes after the age of 30, although signs of HD can become apparent in young children or older adults. In 1983, NINDS-supported researchers discovered the first genetic marker for HD, called G8, on chromosome 4. This important finding in people at risk for Huntington's accelerated the search for the gene, indicated its location at the tip of chromosome 4, and led to development of a presymptomatic test.

Scientists believe that the defective gene causes premature degeneration of nerve cells or neurons in a part of the brain called the striatum. This area is responsible for coordination of movement. Also affected are neurons in the convoluted outer area of the brain, the cortex, which controls thought, perception, and memory. One theory holds that the genetic defect may cause brain chemicals to overstimulate certain parts of these neurons, resulting in nerve cell death. Scientists are trying to solve the mystery behind this process.

In the forefront of the battle against Huntington's disease, NINDS-supported investigators relentlessly hunt the gene's exact location and expect to find it within the next few years. Once the gene is located, scientists hope to understand how it malfunctions, to devise new medical treatments for HD patients,

and, ultimately, to conquer this now incurable disorder. The National Center for Human Genome Research is also supporting research on the development of maps--which show the location of certain identifiable landmarks--of human chromosomes. These should aid scientists in their search for genetic causes of HD and other diseases.

Aiding the scientists in their efforts is the Huntington's Disease Research Roster, which contains genetic information on thousands of volunteer HD patients and their families. Under the direction of NINDS grantee Dr. Michael Conneally of Indiana University at Indianapolis, the roster has provided statistical and demographic data to investigators worldwide and is a critical tool in the search for the HD gene.

Animal Models Expand Knowledge About HD

NINDS investigator Dr. Eve J. Wolinsky of New York University is studying genetic mutations in roundworms as a model of nerve cell degeneration in mammals. Roundworms have very few cell types, but a surprising number of them have counterparts in mammals. Recently, scientists found a rare mutation in a roundworm gene that caused nerve cells to die. When Dr. Wolinsky cloned the gene, it produced a toxic protein that caused a small group of nerve cells to swell and burst. He found a second mutation in this same gene that suppressed the degenerative process. The finding suggests that only a small number of defective genes are involved in degenerative nerve disorders, and helps document in detail the events that occur during cell death. By studying roundworms, investigators hope to learn how mutant genes cause cell death.

A team of scientists working with NINDS grantee Dr. James F. Gusella of the Massachusetts General Hospital in Boston is attempting to build a genetic model of the disorder using transgenic mice (in which genes of another organism have been inserted). The scientists are transferring into mice embryos DNA segments from the regions where the HD gene is thought to lie. If the animals develop the anatomical and biological effects of HD, the mouse model could have a revolutionary impact on HD research.

Researchers Work to Close in on the Gene

The precise location of the HD gene continues to evade a group of investigators from seven laboratories who have joined together in a Collaborative Research Agreement, but year by year, progress is being made. The genetics of Huntington's disease are both unique and complex.

The location of the HD gene is controversial. Previously, scientists believed the gene was located at the tip of chromosome 4 in a region known as the telomere. The telomere, because of its position, is unique and seems to be filled with repeated genes, old viral remnants, and other unexpected sequences whose

function is probably to keep chromosomes separate from one another. In this region scientists have discovered a number of HD markers--easily detectable sequences of DNA that lie near the unidentified gene. The group of investigators have now mapped almost the entire tip of chromosome 4, which includes the telomere. This extraordinary effort has resulted in one of a first well characterized terminal regions of a human chromosome.

Recently, the focus of the search has shifted away from the telomere to a region just a short distance away. Dr. Gusella, who originally discovered the first marker, believes the HD gene is in this second region where he has recently found additional markers. He and others are in the process of mapping this DNA segment that consists of nearly 2 million base pairs (pairs of the chemical subunits that make up the genetic instructions of DNA) and the map is nearly complete.

Dr. Craig Venter and other members of the NINDS Laboratory of Molecular and Cellular Neurobiology, collaborating with Applied Biosystems, have developed new laser technology that can "read" large DNA sequences at a rate of 50,000 base pairs per day. This method will make it possible to determine the order of the base pairs in any candidate gene much faster.

NINDS grantee Dr. Richard M. Myers and a team of investigators at the University of California at San Francisco are using a new technique involving yeast artificial chromosomes (YACs). YACs are tools which scientists use to clone (make multiple copies of) DNA segments exceeding 50,000 base pairs in length. Dr. Myers also is matching various DNA sequences with DNA segments with HD-affected individuals to identify candidate genes.

A team of scientists under Dr. John J. Wasmuth at the University of California at Irvine also is zeroing in on the HD gene. The scientists have isolated several DNA segments containing possible candidate genes. Recently, the investigators found three HD patients with RFLPs--places along the chromosome where a DNA sequence varies among individuals--which act as markers. One of the RFLP markers was very close to the original G8 marker. Dr. Wasmuth distributed the marker to 60 laboratories worldwide for analysis in HD families. As a result, it has been extremely useful for laboratories involved in preclinical analysis of HD.

Studies Target the HD Gene's Effect on Brain Nerve Cells

The immediate consequence of locating the HD gene would be to learn what the gene does and how it triggers cell death in the brain. Some investigators believe the gene may produce a toxic substance in the brain or one that is transported to the brain. Other scientists believe the defective gene may increase the production of certain brain chemicals, which overstimulate their target neurons and cause them to self-destruct.

In 1975, NINDS grantee Dr. Joseph Coyle of The Johns Hopkins University in Baltimore, Maryland, developed an animal model for HD using rats, and found that kainic acid, a toxin derived from seaweed, causes symptoms similar to those in HD. Later, Dr. Coyle found that idebenone, a Japanese stroke drug, protected rats from nerve damage caused by kainic acid. Dr. Susan Folstein, a colleague of Dr. Coyle at the NINDS supported Huntington Disease "Center Without Walls" at The Johns Hopkins University, is now testing idebenone in 60 HD patients to see if it slows nerve destruction.

Excitatory amino acids are brain chemicals that play a crucial role in the transmission of nerve impulses. When found in high levels, some excitatory amino acids cause cell damage and are then known as excitotoxins. Excitotoxins kill nerve cells in the brain, and in animal models, produce the features of several different neurodegenerative disorders. NINDS grantee Dr. Robert Schwarcz of the University of Maryland at Baltimore is studying whether HD is caused by a dysfunction of an excitotoxin called quinolinic acid. Huntington's disease patients have been found to have an increase in the activity of an enzyme called 3HAO, which is involved in the production of quinolinic acid. Dr. Schwarcz, in collaboration with Dr. William O. Whetsell of Vanderbilt University in Nashville, Tennessee, exposed tissue cultures to large doses of quinolinic acid and found significant degeneration of neurons. This work may result in a new class of drugs, called 3HAO inhibitors, that prevent the type of neuronal damage seen in patients with Huntington's disease. Their tissue culture work has also resulted in an ideal system for investigating the importance of brain chemicals in HD.

A related brain chemical, called kynurenic acid, protects the brain against overstimulation of a certain receptor in the brain, known as the NMDA receptor. Many scientists believe that the mechanism of action behind Huntington's disease may involve overstimulation of the NMDA receptor. In addition to his work with quinolinic acid, Dr. Schwarcz is studying the enzymes responsible for the production of kynurenic acid. His work may result in new compounds that trigger or increase the activity of these enzymes, thus taking advantage of their protective features.

NINDS grantee Dr. Flint Beal of the Massachusetts General Hospital recently identified the possible role of kynurenic acid in Huntington's disease. Dr. Beal and his colleagues discovered an abnormality in the level of kynurenic acid in the postmortem brains of HD patients. Using a highly sensitive chemical analyzer, the scientists found that the disease significantly lowered the levels of kynurenic acid. He also found that when normal levels of kynurenic acid are lowered, the NMDA receptor is overstimulated, causing nerve cells to die. This major finding also will help scientists develop better animal models for studying HD, and may lead to new treatments based on regulating NMDA receptor overstimulation.

Research Focuses on Patterns of Nerve Cell Loss in the Brain

Dr. Anton Reiner, an NINDS grantee at the University of Tennessee in Memphis, is studying patterns of nerve cell loss in the striatum. Using postmortem brain specimens of patients with adult-onset and juvenile-onset HD, Dr. Reiner has found that certain types of nerve cells in this part of the brain are more vulnerable to degeneration than others. His studies have shown that patients lose different types of neurons at different rates, and that the more vulnerable neurons are lost in greater abundance during the early and middle stages of adult-onset HD. Data from the study also indicate that losses of certain types of neurons can occur before there are clinical symptoms of HD.

Dr. Reiner's studies suggest that each type of neuron is responsible for certain symptoms associated with different stages of HD. One type may be necessary for the initiation and completion of voluntary movements, and another for the suppression of unwanted movements. As the disease progresses, clinical symptoms such as impaired eye movements, chorea, and rigidity and akinesia (impaired movement) begin to appear, each associated with a loss of a particular type of neuron. Dr. Reiner's studies of the dramatic differences in the losses of various types of neurons have helped to clarify the neuronal basis of symptoms observed in HD. He hopes to discover the specific mechanism underlying both adult-onset and juvenile-onset HD. The information gained from these studies may have therapeutic implications for patients or preventive implications for HD gene carriers, as well as for patients with certain other disorders such as Parkinson's disease.

NINDS grantees Drs. Roger L. Albin and Anne B. Young of the University of Michigan at Ann Arbor are studying the loss of both nerve cells and NMDA receptors in the striatum. The researchers believe that the loss of striatal neurons may result in changes in the density of NMDA receptors in that part of the brain. The depletion of NMDA receptors, the investigators observed, was out of proportion to loss of other types of receptors in the striatum. The study provides further evidence of NMDA receptor involvement in the type of cell death found in HD. The study has documented the pattern of loss of neurons, which causes the involuntary movements and eye movement abnormalities seen in HD patients.

NINDS grantee Dr. Neil W. Kowall of the Massachusetts General Hospital has documented neuronal degeneration outside the striatum in HD. Dr. Kowall found significant reductions of certain neurons in two areas of the cerebral cortex, but did not find a relationship between the severity of HD and extent of neuronal depletion. Dr. Kowall's studies have shown that certain neurons in both the striatum and the cerebral cortex are vulnerable to degeneration in HD, perhaps due to two parallel and simultaneous degenerative processes. While the work of Drs. Young and Albin help document NMDA receptor overstimulation

in the striatum, Dr. Kowall's findings suggest that overstimulation of the NMDA receptor also may occur outside the striatum.

Gaining Understanding Through Patient Studies

Some scientists believe that there may be neuropsychological symptoms of HD that precede the clinical onset of the disease. NINDS grantee Dr. Jason Brandt at The Johns Hopkins University HD center heads the largest presymptomatic testing program for individuals at risk for HD, with 161 persons enrolled. The aim of the program is to determine the long-term psychological and social consequences of disclosing genetic test results to asymptomatic people at risk for HD.

In a recent study, Dr. Brandt screened a large number of individuals over a 3-year period for neurologic and psychiatric symptoms of HD that may precede the clinical onset of the disease. All the subjects were free of clinical symptoms. He compared 18 persons at risk for HD who tested positive for the marker, 51 persons at risk who tested negative for the marker but who have an affected parent, and 15 control subjects. Dr. Brandt found no significant evidence of cognitive, personality, or emotional differences between the two at-risk groups. Refuting the results of previous studies, he concluded that it is premature to believe that there are neuropsychologic impairments in HD that precede the clinical onset of the disease.

The onset of Huntington's disease is often signalled by changes in two types of eye movements. Patients often have trouble following something that is moving in front of them and moving their eyes to notice the sudden appearance of an object or image. Dr. Folstein and her colleagues at the Johns Hopkins University recently developed a sophisticated set of techniques for measuring these changes, which have provided additional means of diagnosing and tracking the progression of HD. Scientists have since applied these techniques as a diagnostic tool for other conditions, such as schizophrenia.

Research Outlook

Scientists supported by NINDS continue to gain insight into the neurochemistry of Huntington's disease. The primary focus of research in this area will center on the most promising of current hypotheses for the mechanism of action behind HD: the neurotoxicity of excitatory amino acids. Based on this work, scientists will add new experimental therapeutic trials to those already underway. Other areas of future research will include working to improve our understanding of the relationship between nerve cell loss and the symptoms of HD; abnormalities of posture and balance in HD; and cognition in HD patients. Scientists also hope to learn why the onset of HD tends to occur earlier as a group in the offspring of affected fathers than in the offspring of HD-affected mothers.

Investigators continue to develop new techniques and equipment designed to quicken the pace of the HD gene search, increasing the likelihood of identifying the gene in the near future. By applying these methods, molecular geneticists are also learning more about other hereditary disorders. Once the HD gene is identified, the larger goal is to determine and correct its fatal flaw. The discovery of the HD gene is near, and brings hope for more accurate testing, possible new treatments, and, ultimately, a cure for this complex and devastating disorder.

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INFANT MORTALITY

	1988 Actual	1989 Actual	1990 Actual	1991 Estimate	1992 Estimate
Public Health Service:					
Agency for Health Care Policy and Research					
Direct.....	\$319,000	\$925,000	\$5,874,681	\$5,252,000	\$9,374,000
Indirect.....	0	0	0	0	0
Total AHCPR.....	319,000	925,000	5,874,681	5,252,000	9,374,000
Alcohol, Drug Abuse and Mental Health Administration					
Direct.....	27,005,000	49,330,000	86,509,000	116,962,000	136,728,000
Indirect.....	0	0	0	0	0
Total ADAMHA.....	27,005,000	49,330,000	86,509,000	116,962,000	136,728,000
Centers for Disease Control					
Direct.....	89,102,500	107,329,500	44,907,000	75,151,000	82,996,000
Indirect.....	0	0	101,092,000	143,963,000	164,659,000
Total CDC.....	89,102,500	107,329,500	145,999,000	219,114,000	247,655,000
Health Resources and Services Administration					
Direct.....	224,978,000	242,885,000	804,849,000	889,885,000	988,909,000
Indirect.....	9,128,591	10,690,997	12,561,773	13,002,858	0
Total HRSA.....	234,106,591	253,575,997	817,410,773	902,887,858	988,909,000
Indian Health Service					
Direct.....	160,518,000	169,479,000	180,890,000	214,386,000	227,970,000
Indirect.....	0	0	0	0	0
Total IHS.....	160,518,000	169,479,000	180,890,000	214,386,000	227,970,000
National Institutes of Health					
Direct.....	108,713,000	120,109,000	138,661,000	159,154,000	182,139,000
Indirect.....	0	0	0	0	0
Total NIH.....	108,713,000	120,109,000	138,661,000	159,154,000	182,139,000

INFANT MORTALITY

	1988 Actual	1989 Actual	1990 Actual	1991 Estimate	1992 Estimate
Office of the Assistant Secretary for Health					
Direct.....	9,612,000	9,502,000	9,590,000	8,039,000	12,250,000
Indirect.....	0	0	0	0	0
Total OASH.....	9,612,000	9,502,000	9,590,000	8,039,000	12,250,000
Total Public Health Service					
Direct.....	620,247,500	699,559,500	1,271,280,681	1,468,829,000	1,640,366,000
Indirect.....	9,128,591	10,690,997	113,653,773	156,965,858	164,659,000
Total PHS.....	629,376,091	710,250,497	1,384,934,454	1,625,794,858	1,805,025,000
Health Care Financing Administration (direct)....	2,500,000,000	2,800,000,000	3,100,000,000	3,500,000,000	3,850,000,000
Total Health and Human Services					
Direct.....	3,120,247,500	3,499,559,500	4,371,280,681	4,968,829,000	5,490,366,000
Indirect.....	9,128,591	10,690,997	113,653,773	156,965,858	164,659,000
Total HHS.....	\$3,129,376,091	\$3,510,250,497	\$4,484,934,454	\$5,125,794,858	\$5,655,025,000

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

INFANT MORTALITY

The purpose of the Agency for Health Care Policy and Research (AHCPR) is to enhance the quality, appropriateness, and effectiveness of health care services and to improve access to that care. This is accomplished through the establishment of a broad base of scientific research and through the promotion of improvements in clinical practice and in the organization, financing, and delivery of health care services. The AHCPR also is responsible for facilitating the development, review, and updating of clinically relevant guidelines for specific conditions and treatments. As the focal point of Federal efforts in medical effectiveness and health services research, the AHCPR seeks to create and disseminate new knowledge and better understanding of the processes by which health services are made available and how they may be provided more efficiently and effectively. The AHCPR addresses the full array of health care issues, among them infant mortality and maternal outcomes.

Medical effectiveness and health services research has been able to identify interventions that are not only effective in addressing certain child health problems, but certain of these have also been shown to reduce future health care costs associated with these problems. Medical effectiveness and health services research has also helped identify those factors that enhance or hinder the successful implementation of these interventions.

Given the very significant roles that State and local governments historically have played with respect to child health, particularly for low-income children, a new look is being taken at the child health programs and policies that these entities have established. Indeed, as medical effectiveness and health services research findings -- including assessments of the experiences of States and localities operating innovative programs -- identify those strategies and interventions that hold the greatest promise for improving child health status, it may be appropriate for individual jurisdictions to rethink and perhaps reorganize their existing activities.

User Liaison Program

The Agency's User Liaison Program developed a workshop for State and local officials entitled, "Designing, Implementing and Financing Health Services for Children." This workshop has been presented three times -- October 1989, June 1990 and October 1990 -- and planning is underway to present the workshop at least once again during FY 1991.

The purpose of the workshop was to provide senior State legislative and executive branch officials, as well as county and local officials, with an in-depth look at health services

research and related information that will allow them to make more informed decisions concerning child health activities carried out within their jurisdictions. This workshop was designed for senior State and local government officials from both the legislative and executive branches who have major responsibilities for policymaking that affects the planning, regulation, financing, delivery and evaluation of health services. It was not intended for officials with specific responsibility for the day-to-day management and operation of child health programs and services, but rather for senior policymakers with broad responsibilities for a range of issues, including child health and welfare.

Through this three-day workshop, State and local officials were provided with an opportunity to:

- o gain a fuller understanding of the nature of the major health problems affecting children, as well as the principal factors which affect child health and survival;
- o review the principal roles and responsibilities that State and local government play with respect to child health and examine the major programs and policies these jurisdiction use to carry out these responsibilities;
- o discuss recent changes in the public and private organization and financing of children's health services and explore their implications for the development of new initiatives at the State and local levels;
- o examine available health services research that identifies opportunities for the development of new programs and policies that can have a positive effect on the health of children as well as those findings which identify approaches that have failed;
- o examine different operational approaches and strategies that individual States or localities have found to be effective in meeting the goals of promoting the health of children in varying settings and across differing age groups;
- o explore strategies which may be used at the State and local level for the evaluation of child health initiatives.

The Workshop included a session entitled, "Strategies to Address Child Health Problems: Pregnancy and Infancy." This session focused on the major health problems of infancy (the first year of life). Because of the profound and long-term impact of a mother's pre-natal experience on the health of her infant, this session also explored in depth the options and opportunities for the promotion of infant health through prenatal policies and programs. The discussion focused on low-birthweight, infant mortality and factors associated with them. Strategies examined included the provision of adequate prenatal

care as well as State and local approaches that have been used to overcome a number of significant obstacles encountered in expanding prenatal care services, namely:

- o difficulty in establishing, operating and funding prenatal care programs and facilitating their maximum utilization;
- o lack of coordination of service delivery across different public programs;
- o an unwillingness of a significant number of physicians to provide prenatal and delivery services to low-income women because of malpractice/liability or reimbursement concerns; and
- o difficulties in establishing and maintaining low-income pregnant women's participation in prenatal care programs.

The discussion of these strategies included an examination of the evidence which exists concerning their effectiveness and costs.

Medical Treatment Effectiveness/Outcomes Research

The goal of the AHCPR's Medical Treatment Effectiveness Program (MEDTEP) is improved effectiveness and appropriateness of clinical practice. The Agency helps to generate scientific and policy-relevant information on the effectiveness of alternative strategies for the prevention, diagnosis, treatment, and management of a wide variety of acute and chronic conditions. In FY 1990, several projects were supported through MEDTEP relating to infant health and maternal outcomes. These include:

"Practice Variations in Prenatal and Intrapartum Care"

Roger A. Rosenblatt, M.D., University of Washington, Grant No. HS06166

This study will explore the relationship between variations in prenatal care received by low risk women in Washington State to provider type (obstetrician, family practitioner, nurse practitioner), location (urban/rural), practice organization and hospital setting. Outcomes to be collected include perinatal mortality, morbidity, and charges. The results will assist in decisions regarding appropriate utilization of prenatal technology for low risk women.

"Regional Variations in Prenatal and Intrapartum Care"

James H. Perrin, M.D., Massachusetts General Hospital, Boston, Massachusetts, Grant No. HS06060

The purpose of this study is to identify and explain documented variations in rates of pediatric hospitalization for five common childhood illnesses (meningitis, asthma and

lower respiratory disease, head injury, toxic ingestion, and acute abdominal pain) in three Northeast cities.

"Effectiveness of Prenatal Care: Two Approaches"

Betsy J. Brach, M.S.N., M.P.H., Johns Hopkins University,
Grant No. HS06605

This project will determine the extent to which comprehensiveness, continuity, and coordination in the delivery of prenatal care affect maternal and infant morbidity.

"Birth Outcomes, Satisfaction with Care and Malpractice"

Frank A. Sloan, Ph.D., Vanderbilt University, Grant No.
HS06499

This purpose of this project is to examine the role of experience rating in medical malpractice. One thousand women will be interviewed regarding their pregnancy and birth experiences five years after the event in order to collect information on outcomes, patient satisfaction, and treatment styles. The experience of patients of physicians with adverse claims experience will be examined against those of physicians with few or no claims against them.

"The Impact of Litigation Risk on Cesarean Section Rates"

Arthur R. Localio, J.D., M.P.H., M.S., Harvard University,
Grant No. HS06677

This study will test the hypothesis that a higher risk of litigation faced by providers of obstetrical care is associated with higher cesarean section rates.

"Obstetrical Decisionmaking in Labor and Delivery"

Emmett Keeler, Ph.D., The RAND Corporation, Contract No.
282-90-0039

This Patient Outcome Assessment Team (PORT) will identify appropriate indications for the use of cesarean section versus its alternatives (oxytocin, trial of labor, assisted vaginal delivery) and analyze variations and correlates of specific diagnostic and treatment procedures utilized in the course of labor and delivery. The emphasis will be on maternal outcomes and on determining factors that influence physicians and patient decisionmaking.

"Gastroenteritis Patient Outcome Research"

Christy Moynihan, Ph.D., SysMetric/McGraw-Hill, Inc.,
Contract No. 282-90-0043

The contractor will evaluate the available literature and data on pediatric gastroenteritis and collect and analyze data to evaluate variations in treatment, outcomes, and resource use. The study population will include

American Indian and Alaskan Native populations. Clinical recommendations will be developed based on findings.

General Health Services Extramural Research

The Agency's Center for General Health Services Extramural Research has a multi-faceted approach to infant mortality concerns. While infant mortality has not been a separate topic area at AHCPR per se, a number of projects have been funded under other priority areas such as health care and the disadvantaged, rural health care, primary care and nursing services research. The Center supports research through peer-reviewed grants and contracts. In addition, the general health services extramural research program provides technical assistance and policy analysis, facilitates timely dissemination of research findings, and works collaboratively with all concerned to assure that activities are coordinated.

Projects Completed in Fiscal Year 1990:

"The Adequacy and Effectiveness of Prenatal Care"

Mary Jo Hansel, Dr.P.H., University of California at Los Angeles, Grant No. HS 06105

This research adds measures of quality to the study of the adequacy of prenatal care, and examines the importance of prenatal care in explaining several measures of pregnancy and birth outcome. The data are from the National Natality Survey and the National Fetal Mortality Survey of 1980.

While health status has a statistically significant relationship with measures of the adequacy of prenatal care, overall, other maternal attributes have an inordinate level of importance in explaining variations in the intensity of care and the kinds of advice that women received. Basically, women in the same socially disadvantaged subgroups that obtained no prenatal care, obtained prenatal care late, or obtained an insufficient quantity of care, also received prenatal care that was of lower quality.

Prenatal care has varying levels and directions of significance in the regressions on maternal health status measures and is not very important in explaining variation in birth weight, length of gestation or fetal survival.

Projects Ongoing in Fiscal Year 1990:

"Use of Perinatal/Infant Services by Hispanics in AHCCCS"

(Arizona Health Care Cost Containment System), Patricia D. Moore, Dr.P.H., R.N., Arizona State University, Grant No. HS 06127

This study is centered on utilization of pre-natal care and infant care the first year of life. The acculturation, health beliefs and utilization of two preventive services (prenatal care and infant immunization and well baby care) are being studied in 310 Mexican-Hispanic families and compared to the health beliefs and utilization patterns of 310 non-Hispanic whites who are also in a state Medicaid program, the AHCCCS program. The findings from this study will provide information on the relationship between acculturate health beliefs and preventive health practices for prenatal and well baby care.

"Low Birthweight and the Quality/Content of Prenatal Care"

Diane B. Petitti, M.D., Kaiser Foundation Research Institute, Grant No. HS 06031

Under the direction of Dr. Petitti this study will examine the association of low birthweight with the earliness, adequacy, quality, and content of prenatal care. This is a retrospective study which will test the hypotheses that the risk from low birthweight is reduced in pregnant women who receive adequate and early prenatal care, receive a screen for bacteriuria and receive assessment and counseling about smoking and substance abuse in pregnancy.

"Physiologic Severity Index for Neonatal Intensive Care"

Douglas Kent Richardson, M.D., M.B.A., Brigham & Women's Hospital, Grant No. HS-06123

An instrument is under development to measure the severity of illness of patients in neonatal intensive care units in order to permit accurate comparative studies of NICU care between hospital, across regions, and over time. The instrument is being developed prospectively, based upon medical records, and according to preliminary analyses, its measures of severity and therapeutic intensity correlate well with mortality, nursing acuity, and physician and nurse global estimates of severity. The measure has been found to be independent of birthweight, and therefore represents a new dimension for investigating outcomes. Extensive refinement and rigorous evaluation of validity and scaling characteristics are expected to be complete by March 1991.

"Mediators of Birth Outcomes Among Three Low-Income Ethnic Groups"

Ruth E. Zambrana, University of California at Los Angeles, Grant No. HS05518

Dr. Zambrana is examining the ethnic differences in birth outcomes among primiparous, low-income Black, Mexican-American and Mexican immigrant women who receive their prenatal care from providers in community health centers and primary care centers in public/private hospitals in Los Angeles, California. The study is designed to

determine if observed differences in medical risks contribute to differences in birth outcomes, if prenatal care influences neonatal outcomes when medical risk is controlled, if stress and anxiety contribute to birth outcomes, and if the three groups differ in the social support they receive during pregnancy.

"Pediatric AIDS: Local Responses, Service Use, and Cost,"
Allison-Cooke, Sherry, Ph.D., National Perinatal Information Center, Grant No. HS 06271

This project will provide both longitudinal and cross-sectional data about the utilization and costs of inpatient and outpatient care for infants, children, and women with AIDS. One aspect focuses on discharge, billing, and cost data from 10 hospitals in 5 urban areas with high incidence of pediatric AIDS and will analyze trends from 1987 to 1991. In addition, detailed case studies will be developed to address questions about alternate community responses to meeting the health care needs of women and children with AIDS and to obtain information on outpatient services.

"AIDS Cost and Service Utilization Survey" (ACSUS) Westat, Inc., Rockville, MD, Contract No. 282-89-0020

ACSUS is a national survey to collect uniform data on the utilization and costs of health and social services for persons with AIDS and other HIV-related illnesses. Interviews will be conducted every 3 months over an 18-month period, with a sample of approximately 1900 adults and adolescents plus 100 children. In addition to medical care, respondents will be asked about their use of social, mental health, and oral health services, informal social supports, barriers to care, employment history, and quality of life. Interview data will be supplemented by information abstracted from patient records and information supplied by providers and insurers.

These sources will provide a comprehensive picture of the direct and indirect costs of medical and support services, during various stages of HIV-related illness. Data will include third-party and out-of-pocket payments, for both inpatient and outpatient care, including care received in physicians' offices, ambulatory clinics, and the patient's home. Utilization and charges for the services of physicians, nurses, and other health care workers will be obtained, as will charges for drugs, medical supplies, and devices.

Final products of the contract will include documented data tapes for use by the research community. In addition, ACSUS data will enhance AHCPR's capacity to provide timely input to policy questions. The data will support

examination of utilization, cost, and access across HIV exposure categories (e.g., homosexual, heterosexual, or intravenous drug use), stage of illness, demographic characteristics, geographic area, and payment source. By addressing the full spectrum of HIV-related illness and the range of health care providers and payers, ACSUS will provide a rich source of data for research and the basis for policy-relevant analyses concerning the utilization and costs of health care services associated with HIV illness.

New Starts in Fiscal Year 1990:

"Consequences of Patterns of Provider Care for AIDS,"

Turner, Barbara; Thomas Jefferson University, School of Medicine, Grant No. HS 06465

This project will examine specific patterns of outpatient provider care for AIDS patients of all ages who are New York or California Medicaid enrollees. Four groups of Medicaid enrollees will be studied: homosexual or intravenous drug user (IVDU) men, women, and children. A severity of illness index will be developed for children with AIDS following a similar process used for adults.

"Socioeconomic Factors in Birth Outcomes: The U.S. and France"

Embry Howell, Individual (Dissertation), Grant No. HS 06621

This study will investigate the relationships between socioeconomic factors and birth outcomes in the United States and France. France was chosen for comparison because it has a large and socioeconomically diverse population, a health service delivery system similar to that of the U.S., but a health care financing system that differs substantially. All pregnant women have health insurance coverage in France. Low birth weight and associated infant mortality are issues of great concern for public health policy. The data should aid policy formulation in the important area of improving the access to prenatal medical and health services for poor people.

"Full Term Intensive Care Survivors: Outcome Assessment"

Marie McCormick, M.D., Brigham and Women's Hospital, Grant No. HS 06523

This is a study of outcomes of full-term infants weighing over 2500 grams at birth, admitted to the NICU, and surviving to age six months. A six-month outcome assessment conducted by telephone interview with the parents will be attempted for those infants known to survive. The relationship between neonatal characteristics and outcomes of development and general health, and the relationship between current health status and health care resource utilization will be explored.

"Nursing Interventions to Improve EPSDT Testing,"

Maija L. Selby, Dr. P.H., R.N., University of North Carolina, Grant No. HS 06507

The long term goals of this study are to improve health and reduce health care costs for children of low-income families by increasing utilization of Early and Periodic Screening, Diagnosis and Treatment (EPSDT), a federal program of comprehensive health promotion and disease prevention services for Medicaid-eligible children from birth to age 21. The specific aim of the study is to test the effectiveness, cost-effectiveness, and efficacy of Public Health nursing interventions to improve utilization of EPSDT in rural North Carolina.

"Racial Differences in APGAR Scores and Infant Mortality,"

Mary P. deHart, Johns Hopkins University, Grant No. HS 06609

The objective of this research is to assess possible racial differences in the association between one minute and five-minute APGAR scores and the mortality and early morbidity in low birthweight infants. The findings may assist in the predictive use of the one and five-minute APGAR score for treatment protocols and outcome, and explore the influence of race on both treatment and outcome.

"Doctor/Patient/System Relationships and Perception of Quality,"

Roy Penchansky, University of Michigan, Grant No. HS 06217

To examine a set of factors that affect the probability of malpractice claims by patients experiencing poor outcomes of surgery, miscarriages, babies born with malformations or adverse reactions to drugs. This project will contribute significantly to knowledge of factors that predict whether an unexpected event is likely to lead to a malpractice claim. This knowledge may make a risk management program possible.

"Medicaid Policy and Infant Survivability,"

Grace Poertner, M.S.W., (Dissertation) Individual, Grant No. HS 06627

The objective of this study is to determine if an infant's chance of survival to one year of age, given individual socioeconomic factors, is improved when Medicaid programs include: the medical need option; greater coverage of the poverty population; and/or increased Medicaid expenditures for AFDC adults. Merged vital statistics data (1984 Live Birth cohort) and Medicaid data will be used for running logistic regression analyses in the context of health care utilization model developed by Ronald Anderson and Associates. By looking in a broad-based way at the impact of Medicaid on infant mortality and survival this dissertation could contribute significantly to the health

ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION

Infant Mortality

Drugs such as cocaine, heroin, marijuana, crack, and PCP, as well as nicotine and alcohol, readily cross the placental barrier. When used during pregnancy, they can cause profound and potentially irreversible damage in the newborn. Research has shown that many of these drugs alone, or in combination, may contribute to an increased incidence of retarded fetal growth, premature birth, low birth weight, Sudden Infant Death Syndrome, and Neonatal Withdrawal Syndrome. Drug and alcohol use by pregnant mothers is considered a possible factor contributing to the poor U.S. infant mortality rate.

National Institute on Drug Abuse

The incidence of infant mortality associated with maternal drug abuse is not yet clear, but research results certainly show that drug abuse by pregnant women can harm their children. In addition, injection drug abuse by pregnant women can result in perinatal transmission of HIV. NIDA's research program is currently focusing on identifying risks, to both mother and child, of maternal drug use before and during pregnancy; on developing more efficacious treatment programs for pregnant women; on developing new drug abuse treatment medications that will either not affect or have few effects on the fetus; on improving treatments for drug exposed infants; and on developing better prevention programs that encourage women not to use drugs.

Epidemiology

According to results of the 1990 National Household Survey on Drug Abuse, nearly five million of the 60 million women 15-44 years of age, the childbearing years, have tried an illicit drug at least once during the past month. Of these, over half a million reported using some form of cocaine and 3.9 million said they used marijuana during the past month. Although accurate estimates of the incidence of the use of specific drugs especially during pregnancy do not exist, it has been estimated that as many as 375,000 infants may be born to women who used one or more illegal substances during their pregnancy.

A NIDA researcher reported this year that among 715 pregnant women screened for drug use in Pinellas County, Florida, overall illicit drug use prevalence was 14.8 percent: 15.4 percent in White women and 14.1 percent in Black women. However, Black women more frequently used cocaine (7.5 percent) than White women (1.8 percent), while White women used marijuana more frequently (14.4 percent) than Black women (6.0 percent).

New efforts directed at obtaining more accurate data on the prevalence of drug abuse among pregnant women were initiated this

year. One such project is the In Utero Drug Exposure Survey. This is a hospital based study that will assess the extent to which babies are born physically drug dependent or suffering consequences due to prenatal drug exposure. Consequences being examined include addiction, withdrawal, congenital abnormalities, growth retardation, perinatal complications, and neonatal behavior alterations. This survey will help determine the prevalence of prenatal exposure to all major drug types, the temporal patterns of that exposure, and the demographic characteristics of both infants and mothers. Results from this study will yield information identifying women who are at risk of drug abuse during pregnancy, and will aid policy formation and public health efforts to prevent and treat drug abuse as early as possible.

Biological Studies

All major classes of drugs of abuse are known to cross the placenta and influence the development of the fetus, the course of pregnancy, and subsequently human development. NIDA is investigating the magnitude, mechanisms, and duration of the direct effects of drugs on the fetus. Biological studies are now underway that examine the effects and functional significance of drug-specific fetal exposure on the development of neuro-endocrine, cardiovascular, renal, hepatic, immune, and other physiological systems in the newborn and developing child. Genetic effects, including ways in which to identify and characterize genes and gene products that might be involved in an individual's later life response to drug ingestion, are also being conducted. The characterization of how fetal or early life exposure to drugs may alter gene expression in future generations is also of interest.

Opiates: Mothers are not the only contributors to the health of their offspring. One study currently in press, examines the effects of adolescent morphine exposure on the sexual maturation of male rats and the development of their progeny. Results indicated that morphine exposure during adolescence led to a pronounced inhibition of sexual maturation. When rats were bred with drug naive females, litter sizes were decreased in comparison with controls. Although morphine-derived male offspring had normal serum corticosterone levels, significant increases were found in female morphine-derived offspring. These data suggest that exposure of male rats to opiates during adolescence can markedly influence sexual maturation and can have long-term selective and sex-specific effects on the development of both male and female offspring.

Cocaine: Infants with reported adverse obstetrical and neonatal effects of prenatal cocaine exposure (abortion, premature delivery, low birth weight, small for gestational age, and neurodevelopmental defects) have been followed for up to two years. These children scored poorly on developmental tests that measure ability to concentrate, interaction with others, and

ability to cope with an unstructured environment suggesting that these children may require a structured learning environment and patient one-on-one attention from teachers and care-givers.

Preliminary evidence for adverse effects of cocaine use on human male sexual maturation is reported researchers at Yale. These investigators found that adult men who used cocaine for two years had decreased sperm counts; five year use caused, in addition, loss of sperm motility and sperm dysmorphology.

Marijuana: Previous reports suggest that marijuana use is associated with lower infant birth weight and shorter length. Based on preliminary analyses of a multi-year study, it was recently reported that memory in children up to four years of age can be impaired, in a dose-dependent fashion, by in utero exposure to marijuana. Interestingly, no memory impairment was observed in these children at 1, 2, or 3 years of age. This suggests that normal appearance at early ages does not necessarily preclude later impairment.

PCP: A refined analysis of 36 phencyclidine (PCP) exposed and 26 control full term infants matched for same area residence, ethnicity and economic levels revealed the following: 1) Head circumference measured at birth continued to be significantly smaller at 6 and 15 months for 40 percent of the PCP exposed group. At 15 months the PCP exposed group did not perform as well on developmental tests of cognition. 2) The PCP-exposed group at 6 months demonstrated much less play behavior, and this finding was particularly obvious if the infants were still living with their biological, drug dependent mothers. Motor problems detected at 6 months involved movements such as tremors, tongue thrusts, and hitting self with toys. Visual attention was also altered. For example, when unfamiliar stimuli were presented to these infants, they did not indicate a preference or interest in the novelty aspect of the objects. 3) Objective, home observation behavior rating scales, recorded at 3 and 9 months, indicated that PCP abusing women are less sensitive to the needs of their babies. This latter finding suggests that, as the infant grows into toddlerhood, the mother remains psychologically unable to provide total care. Thus, the importance of continued treatment interventions by "significant others" cannot be underemphasized for these at-risk infants; also, continued treatment for the drug-impaired mother is essential.

Perinatal Transmission of AIDS

Over 80 percent of all reported pediatric AIDS cases are attributed to transmission from a mother with, or at-risk for, HIV infection. Drug abuse is a major contributing factor in mother-to-child HIV transmission. One-half of pediatric AIDS cases linked to maternal transmission involve women who used drugs intravenously, and an additional 21 percent involve women with sexual partners who are injection drug users.

Mechanisms of transmission of HIV from mother to child is of primary interest. In addition, methods of early detection of HIV infection of the newborn and infant are vital to ensuring the earliest possible intervention. Because the predominate technology for detecting HIV infection is based on the detection of antibodies to HIV, one of the major blocks to assessing infant infection is the presence of maternal antibodies to HIV in the infant for up to one year after birth. Research on methods to circumvent this difficulty are under investigation. Issues concerned with perinatal transmission of AIDS are discussed in detail in the pediatric AIDS section of this report.

Maternal and Infant Treatment

The overall goal of any treatment for addicted women and their offspring is to prevent drug abuse at or before conception; and, if not then, to intervene with effective therapeutic programs for the women to prevent further illicit drug use and reduce the number and extent of the developmental difficulties experienced by their children. The drug abuse prevention and treatment context offers the opportunity for intervention strategies aimed not only at drug use, but also directly at prevention of HIV infection (e.g., safer sex practices education, self-esteem development, empowerment training). Additional special efforts may be necessary to reach women who themselves are not IV drug users, but who are the sexual partners of IV drug users.

Although neonatal drug withdrawal syndromes and subsequent infant neurobehavioral impairments have yet to be fully described, present knowledge provides a basis for clinical treatment of affected newborns, therapeutic interventions to ameliorate developmental delays and disabilities and, possibly, the prevention of drug-induced fetal effects from disabling the child.

Substantial barriers to treatment still remain. At present too few drug abusing women receive prenatal medical care and too few obstetrical patients with drug-related problems receive adequate treatment for their drug abuse. NIDA is participating in a coordinated effort with the Association for Medical Education and Research in Substance Abuse (AMERSA) and Brown University Center for Alcohol and Addiction Studies to train physicians, including practitioners in obstetrics and pediatric medicine, to diagnose and treat drug addiction as well as the multiple related problems. Along with these efforts to increase awareness on the part of all health care providers of the potentially serious consequences of maternal drug abuse on offspring, NIDA is supporting the scientifically based evaluation of ten comprehensive treatment programs for drug abusing pregnant and postpartum women and their infants. These programs provide a full array of medical care and social services.

Although more comprehensive programs are becoming available throughout the country, there are still numerous difficulties

identifying addicted pregnant women and admitting them to and retaining them in traditional services or even in new and innovative combined clinical services. To address these complex issues, NIDA supports a number of studies that aim to eliminate some of the barriers to treatment through the development and evaluation of referral systems and intensive community outreach programs. In addition, several therapeutic programs offer mothers the opportunity to live in safe "drug free" housing with their infants and young children while undergoing treatment.

National Institute on Alcohol Abuse and Alcoholism

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) supports research pertaining to the role of alcohol in infant mortality, including the impact of alcohol during pregnancy, the effects of alcohol on the nutritional needs of the newborn, and the susceptibility of children with fetal alcohol syndrome (FAS) to high morbidity and mortality. Since FAS babies are low birth weight, and low birth weight is a major risk factor for infant death, FAS babies suffer high mortality rates.

Human epidemiological and laboratory animal studies have shown that alcohol consumption during pregnancy is associated with a variety of adverse outcomes, depending on the amount and duration of drinking. The most severe outcome is FAS, a cluster of defects that includes growth deficiency, central nervous system impairments, and characteristic abnormal facial features. Other reported effects include increased spontaneous abortions, stillbirths, growth retardation, physical anomalies, and subtle developmental, behavioral, and cognitive deficits. Low birth weight, which is strongly associated with infant mortality in the first year of life, is a frequently reported effect of prenatal alcohol exposure.

The incidence of FAS is estimated to be 1-3 cases per 1,000 live births. Partial manifestations of the syndrome, called fetal alcohol effects (FAE) or alcohol-related birth defects, are estimated to be about three times more frequent. The cost of providing care for individuals with FAS-related mental retardation and birth defects is estimated to be about \$321 million per year. Early intervention to prevent or reduce drinking during pregnancy can reduce the occurrence of FAS and FAE.

Extramural Research

Basic research supported by the NIAAA include assessment of offspring outcomes; determination of dose response thresholds and critical periods of risk during in utero development; identification of factors mediating susceptibility; and elucidation of the underlying mechanisms of alcohol-induced damage. The goal of fetal alcohol research is the identification of women at risk and the development of therapeutic interventions leading to reduced incidence or even prevention of the effects.

Is There a Period During Pregnancy When Alcohol Consumption is Safe?

Previous work has shown that blood alcohol concentration may be the critical factor for inducing alcohol-related birth defects. Recently, a rat model that simulated binge drinking in the human third trimester was used to demonstrate that a given dose of alcohol consumed in a short period can cause more damage to the brain than the same amount of alcohol consumed at regular intervals throughout the day. The severity of damage was related

to the maximal blood alcohol concentration and not to the absolute amount consumed.

Alcohol and Fetal Nutrition

The developing fetus receives nutrients essential for growth and development through the placenta. The transport of amino acids, vitamins, minerals, and carbohydrates across the placenta to the fetus may require special protein carriers or enzyme systems. The possible role of alcohol-induced impairment of placental transport function or fetal metabolism of nutrients in growth retardation and birth defects is an important research area. For example, folic acid (a B vitamin) deficiency can cause one form of anemia during pregnancy, and this may result in decreased fetal growth and development. Since chronic alcoholics may also exhibit folate deficiency, this condition may contribute to low birth weight in offspring of alcoholic mothers. One project is studying the mechanism of placental folate transport. A magnesium-dependent protease (an enzyme that degrades protein) that may be involved in the regulation of folate transport was recently identified.

Decreased fetal-placental blood flow has been shown to be associated with intrauterine growth retardation, a cardinal feature of FAS. In vitro studies with human umbilical cord and in vivo studies in monkeys demonstrated impaired umbilical circulation due to spasms and collapse of the umbilical vessels following exposure to alcohol. The resulting decrease in oxygen availability to the fetus (hypoxia) may lead to adverse effects on the fetus.

Alcohol Affects Nutritional Needs of the Newborn

Breast feeding has many beneficial nutritional and immunological effects for the newborn. The major hormone controlling milk synthesis is prolactin. The effect of single intoxicating doses of alcohol on prolactin release has been examined. Although basal levels of prolactin is not affected, prolactin release induced by nursing is temporarily inhibited.

FAS Children More Susceptible to Infection

Children with FAS are more susceptible to bacterial infections, which may be related to impaired immune function. Research suggests that exposure to alcohol either in utero or through breast milk may lead to impaired immune function, thus contributing to infant morbidity and mortality. In one study, young rats prenatally exposed to alcohol exhibited diminished immunological response. Another study of maternal to infant transfer of cell-mediated immunity through breast milk showed that maternal ethanol consumption prior to infection with a parasite diminished the effectiveness of lactational transfer of immunity.

Alcohol and Maternal-Fetal Hormonal Interactions

Growth and development of the fetus are regulated by maternal and fetal hormones and growth factors whose complex interactions may

be disrupted by exposure to alcohol. Researchers recently reported reduced birth weights for rat pups whose mothers received alcohol and the male hormone testosterone at the same time. Since alcohol is known to stimulate the neuroendocrine system, a synergistic effect between endogenous hormones and maternal plasma testosterone levels was suggested. Thus, individual differences in basal and stimulated hormone levels of the mother may be a contributing factor in low birth weight in alcohol-exposed children. Once the effects of prenatal alcohol exposure on hormonal regulation are fully understood, it may be possible to develop appropriate hormonal therapeutic measures to prevent alcohol-related growth retardation.

Center on Neurobehavioral Aspects of Fetal Alcohol Exposure

Recognizing the need for a focused multidisciplinary effort to address questions related to fetal alcohol exposure, and the need for a nationally recognized resource, the NIAAA funded an alcohol research center devoted to the subject in FY 1987. One study is using recombinant DNA technology to identify possible alcohol-metabolizing enzyme genotypes in drinking mothers and fetuses that predispose to fetal injury. In a small sample of mother-child pairs, no correlation between FAS and a variant aldehyde dehydrogenase was found. Other research includes the biochemical characterization of human placental alcohol-metabolizing enzymes to determine whether genetic differences influence fetal outcome; and studies of effects of alcohol on human umbilical artery contractility, blood flow, and associated hypoxia.

National Maternal and Infant Health Survey

In response to the urgent need for updated epidemiological data on the incidence and prevalence of fetal alcohol effects, the NIAAA was a cosponsor of the 1988 National Maternal and Infant Health Survey (NMIHS) conducted by the National Center for Health Statistics. The maternal survey questionnaire contained five questions related to alcohol consumption. The questionnaires for hospitals and prenatal care providers also contained elements relevant to alcohol use. Certificates of live birth and of fetal death adopted by 10 states asked about alcohol use during pregnancy, and the birth certificates identified fetal alcohol syndrome as an abnormal condition. Data from the NMIHS will be used by NIAAA to determine the effects of maternal drinking of alcohol beverages on infant morbidity and mortality.

Office For Substance Abuse Prevention

In response to the growing crisis of substance abuse by pregnant women and its impact on unborn children, the OSAP has undertaken education and prevention initiatives designed to target specific at risk populations. The overall goal of these efforts is to decrease the use of drug and alcohol abuse by pregnant women with a corresponding decrease in infant mortality and the number of infants born drug impaired.

A major effort in this area is the Model Demonstration Program for Pregnant and Post-Partum Women and Infants. This program is intended to increase the availability and accessibility of prevention and treatment services to pregnant women and their infants by either direct service delivery and/or promoting the involvement and coordinated participation of multiple relevant organizations in delivery to needed services to these populations. Services provided by OSAP grantees range from pre-pregnancy counseling, to early intervention for the pregnant mother, to routine pediatric exams and other care for the infant after birth.

In addition, OSAP disseminates, through the National Clearinghouse for Alcohol and Drug Information (NCADI), information about the effects of alcohol and other drugs on pregnancy and newborns to a wide range of professionals, health care providers, other Federal programs such as the Women, Infants, and Children program, and the general public. The intent of this effort is to provide accurate, timely, and culturally relevant information on the impact of alcohol and other drugs on the pregnant mother and the unborn infant.

OSAP is establishing a National Perinatal Addiction Resource Center to stimulate effective policies and practices for preventing and addressing maternal substance abuse and its consequences on infants and children. The Resource Center has four objectives which are designed to decrease infant mortality: to examine and improve service delivery strategies; develop a national network of experts and practitioners; provide training experiences on community-based prevention; treatment, and rehabilitation; and establish a national data base system for monitoring activities of the center.

OSAP also promotes, through conferences, networking and information sharing, activities related to maternal substance abuse issues that have a potential for significantly impacting on the well being of infants and on infant mortality. During the past year OSAP held a National Conference on Healthy Women, Pregnancies and Infants. Over 400 policy makers, prevention practitioners, and administrators met to heighten awareness for the need for programs targeted to substance abusing pregnant women and their infants; to assure appropriate diagnosis and treatment of clients recognizing the high degree of co-morbidity among this population; and to present state-of-the-art programs,

practices and emerging lessons learned from the use of such strategies. OSAP also sponsored a conference on Alcohol and Drug Dependent Women, and Their Children. Participants outlined specific strategies and projects that can be implemented by Federal, State, and local governments and private non-profit and for profit organizations to enhance prevention and treatment efforts for pregnant drug abusing women, their infants and children.

Many drug exposed infants are difficult to care for during the first few months of life. Given the recent epidemic of drug abuse among pregnant women, information is now, and only slowly, becoming available on the far-reaching effects that drug use during pregnancy appears to have on children. Longitudinal studies designed to follow these children as they develop are now underway. Early findings indicate that the children tend to run increased risk of learning disabilities and delayed motor, speech, and language development.

One longitudinal study of pregnant women who used cocaine during pregnancy found, after two years of observation, that their children have poor concentration, difficulty in interacting with other children, and are unable to cope with an unstructured environment. This suggests that these children will require a structured learning environment and patient, one-on-one attention from teachers and caregivers in order to achieve maximum learning potential. Another longitudinal study found that neuro-development, particularly cognition and memory, is impaired in 4 year old children who were exposed in utero to marijuana. Several other longitudinal studies are underway examining the consequences of drug abusing pregnant women, and additional findings can be expected over the next several years.

Office for Treatment Improvement

The problem of substance abuse in pregnancy has dramatically escalated over the past decade. OTI has dedicated considerable effort to decreasing infant mortality by identifying the risks of maternal drug use to the mother and child. By improving treatment programs for pregnant women, and, by identification of pregnant women within specific programs and providing specialized treatment for them, OTI can impact on decreasing the maternal medical and obstetrical complications that lead to increased premature birth and the potential for infant mortality.

ADMS Block Grant

The Alcohol, Drug Abuse, and Mental Health Services (ADMS) Block Grant, administered by OTI, requires the States to use not less than 10 percent of the entire amount of the Block Grant to provide alcohol and drug abuse services designed for women (especially pregnant women and women with dependent children) and demonstration projects for the provision of residential treatment services to pregnant women.

The legislation does not specifically address the matter of alcohol and drug abuse services to improve infant mortality, however many of the women receiving services through the Block Grant and the set-aside are in their prime child-bearing years. Recent data from the National Association of State Alcohol and Drug Abuse Directors indicate that of those women in publicly-funded alcohol and drug abuse treatment programs, almost 75 percent are between the ages of 18 and 34.

It is difficult to estimate the percent of set-aside funds spent specifically on pregnant women, yet annual reports for FY 1989 (the first year provision was made for services to pregnant women) indicate increased numbers of programs and services directed to this underserved population. New services directed to women include attention to minorities, rural, Hispanic, Native-American, criminal justice, indigent, and adolescent sub-populations, throughout the Nation.

As part of its ongoing effort to strengthen Federal control and accountability for the ADMS block grant, OTI has developed a State Systems Development Program (SSDP), that involves: 1) the conduct of State treatment demand and capacity assessments, 2) development of Statewide treatment improvement plans, 3) on-site performance monitoring and targeted technical assistance, and 4) creation of a national data base of current State treatment information. The SSDP will focus on assessing the incidence and prevalence of addictive disorders among perinatal women and their substance-exposed infants and children. The SSDP is designed to provide targeted assistance to State and local governments such that the health and human services safety net is strengthened for women, infants and children.

OTI and the Office for Substance Abuse Prevention (OSAP) have placed extensive emphasis on improving services and collecting data on pregnant women as a national priority population, with a variety of survey mechanisms currently in the field. States continue to indicate that current services are not adequate to meet the needs of women substance abusers. However, the increased numbers of women in alcohol and drug abuse treatment noted over the last several years, and newly targeted prevention activities, reflect a strong Federal/State commitment to enhance services to women (including women of child-bearing ages and pregnant women), which may positively impact future infant mortality rates.

Waiting List Grant Program

A number of additional activities within OTI will contribute to decreasing infant mortality. The FY 1991 grant announcement of the Drug Abuse Treatment Waiting Period Reduction Grant Program (intended to reduce waiting lists by increasing treatment slots) contains a focus on pregnant and post-partum women. Extra consideration is given to applicants who would expand existing treatment slots for pregnant and post-partum women or add a new treatment component for this population where none previously existed. Additionally, all women's components to be funded must include medical services.

Critical Population Grant Program

Nine funded grants in the FY 1990 Critical Populations Grant program specifically emphasized services for women. These include public housing projects, residential treatment facilities and outpatient modality. These projects are located in the following cities: Pittsburgh, Philadelphia, Nashville, Jacksonville, El Paso, Pamona, San Francisco (2 projects), and the Bronx. These projects include one or more of the following: medical services, child care, education services, vocational development, parenting classes, HIV counseling and testing, linkages to other social and medical services.

Treatment Grants to Crisis Areas

One of the four mandatory activities of the Treatment Grants to Crisis Areas (Target Cities) Program that will be required of the eight selected cities is to focus on developing or improving treatment services for pregnant women and drug abusing females and their children. The cities funded include: Boston, New York, Baltimore, Atlanta, Los Angeles, Albuquerque, Milwaukee and San Juan. All the selected cities will integrate primary care and substance abuse treatment, specifically addressing the needs of pregnant women and the critical interrelationship between treatment and medical/obstetrical needs. These OTI activities, which address the needs of the substance abusing female, will have a significant impact on decreasing the infant mortality rate in this population.

CENTERS FOR DISEASE CONTROL
OFFICE OF THE DIRECTOR, HUMAN IMMUNODEFICIENCY VIRUS

Infant Mortality

School Health Education

CDC continues to support a program, School Health Education to Prevent the Spread of HIV Infection, designed to help school personnel and others plan, implement and evaluate effective education about AIDS and HIV infection for youth. The schools are a particularly important focus for HIV prevention efforts as more than 45 million young people are currently enrolled in some 100,000 elementary and secondary schools across the country and more than 12 million additional students are enrolled in colleges and universities. The program enables schools, and organizations serving youth not in school, to identify and develop effective HIV prevention educational strategies that are consistent with community values and needs.

CDC has established cooperative agreements with 23 national organizations to increase the number of schools, and agencies serving youth not in school, that provide effective HIV prevention education. Several of these organizations target black and/or Hispanic youth, incarcerated youth, runaway youth, and college and university populations.

Cooperative agreements have also been established with 55 State and territorial and 16 local education agencies in jurisdictions with the highest cumulative number of reported AIDS cases to provide locally-determined prevention education for school-aged populations. Two State and one local education agency receive additional funding to support training/demonstration centers. These centers provide training to State and local education agency representatives from across the country on how to implement effective HIV education in their school systems.

In fiscal year 1990, CDC began a new program to increase the number of colleges and universities that provide HIV prevention education and to increase the number of college students who receive HIV prevention education. Five universities in selected States with a high incidence of reported AIDS cases received financial and technical assistance from CDC to establish an HIV education consortium among other schools within the State. Each funded school is planning to conduct the following activities: (1) disseminate materials; (2) train staff and students; (3) coordinate HIV prevention programs in the State; and (4) monitor HIV prevention education.

The AIDS School Health Education Subfile, part of the Combined Health Information Database, became operational in 1987. As of April 1990, the annotated bibliography of the AIDS Subfile contained over 600 abstracts of curricula, policies, teaching materials, and programs related to AIDS and HIV. The subfile provides educators across the Nation with ready access to a wide variety of materials developed at the national, State and local levels.

CENTERS FOR DISEASE CONTROL
CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION

Infant Mortality

Introduction

CDC conducts surveillance and epidemiologic investigations, and provides program development and technical assistance, to reduce perinatal, neonatal, and postneonatal mortality and morbidity related to low birth weight, sudden infant death syndrome (SIDS), prematurity, congenital defects, and complications of pregnancy. In partnership with States, efforts are directed at reducing adverse pregnancy outcomes by identifying risk factors and developing and evaluating interventions to target these factors. Analytic support is provided to link birth/death certificates with key Maternal and Child Health (MCH) Program data to permit monitoring of program coverage, targeting, and effectiveness.

Prevention Surveillance Efforts

I. Surveillance

To help States better address the infant health issues outlined above, a comprehensive surveillance system has been initiated to (a) identify those populations at highest risk, (b) enable States to target their intervention efforts, and (c) provide a data resource for evaluating progress toward the Year 2000 Objectives related to low birth weight and infant mortality. Two substantial surveillance enhancements to better address these infant health issues have been initiated in recent years:

- o Pregnancy Nutrition Surveillance System (PNSS): an ongoing program-based surveillance system designed to monitor the prevalence of nutrition-related problems and behavioral risk factors among high-risk prenatal populations. This effort, initiated in 1979, is designed to improve the management of State prenatal programs. To be expanded in selected States in 1991 and 1992.
- o Pregnancy Risk Assessment Monitoring System (PRAMS): initiated in Fiscal Year 1987. PRAMS is State-based surveillance of maternal behaviors during pregnancy and the child's early infancy. It is being carried out through cooperative agreements in Indiana, Maine, Michigan, Oklahoma, West Virginia, and the District of Columbia. In addition, PRAMS project staff are providing technical assistance to the States of Alaska and California as these States implement PRAMS with their own resources. In 1991 and 1992, will be expanded from 8 States to a total of approximately 26 States.

PNSS and PRAMS are significantly increasing the capacity of States to monitor health-related behaviors associated with poor pregnancy outcome, use the information to direct intervention efforts more precisely and efficiently to areas and populations in greatest need, and maximize the use of readily available clinic information for programmatic purposes.

II. Research into the Black/White Gap in Infant Mortality

In FY 1991 and FY 1992 CDC is expanding research activities on racial disparities in infant mortality and low birth weight to include a study of pregnancy outcome among black and white enlisted women in the military. A second focus of research will involve studies that will examine psychosocial and physiologic effects of being Black in the U.S. on pregnancy outcome.

111. State Capacity Building for MCH Epidemiology and Surveillance

Maternal and Child Health Epidemiology Program: Because programs to reduce infant mortality are implemented at the State level, an essential CDC function is to improve the State capacity to conduct surveillance, investigations, program evaluation, and prevention efforts, as well as improve service delivery. CDC provides technical assistance for States to target and effectively serve high-risk groups. The Maternal and Child Health Epidemiology Program (MCHEP) was developed and implemented in collaboration with the Health Resources and Services Administration. Over the past 5 years, long-term support has been provided to five States (Mississippi, Alabama, South Carolina, Georgia, California) and the Commonwealth of Puerto Rico through the assignment of epidemiologists to work with maternal and child health directors. Short-term assistance has been provided to New York City, New Jersey, Kentucky, West Virginia, Arkansas, Iowa, Hawaii, Montana, Utah, Puerto Rico, and the District of Columbia.

Centers for Healthy Infants and Pregnancies: Using resources from the 1991 Infant Health Initiative, CDC will initiate a new expanded program of technical assistance to States in 1991 through the development of Centers for Healthy Infants and Pregnancies (CHIPS) in selected States. CHIPS will provide an opportunity for State health departments to work with CDC and other local, State, federal and private organizations to formulate appropriate goals and objectives, conduct surveillance and epidemiologic investigations and evaluations of reproductive health problems, develop and implement effective interventions, conduct evaluations of service programs, and build capacity in States to conduct surveillance and research and translate surveillance and research findings into effective interventions.

IV. Prenatal Smoking Cessation Projects

The Prenatal Smoking Cessation (PSC) projects are designed to share the experiences gained by CDC personnel from CDC demonstration projects and other trials in planning, implementing, and evaluating prenatal smoking cessation programs in State and local health departments. For example, the Smoking Cessation in Pregnancy Research and Demonstration (SCIP) project, a program of assistance to the States of Colorado, Maryland, and Missouri to develop new smoking cessation interventions for pregnant women, has enabled the following accomplishments:

- o State-of-the-art interventions have been developed that require no additional staff to implement, and include patient counseling at

every visit, self-help materials, and individual guidance identifying support for stopping smoking. Urinary cotinine tests are being performed to biochemically validate each woman's smoking status at the three study points.

Preliminary results from two States are encouraging: women attending intervention clinics are more likely to quit smoking by the 8th month of gestation than women attending control clinics (Colorado: 13.8% of women in intervention clinics quit smoking versus 9.5% in control clinics; in Missouri these rates were 14.4% versus 10.6%).

- o States are committed to continuing the smoking cessation interventions after the demonstration phase, extending the program to include those clinics now serving as controls.

The process of technology transfer for prenatal smoking cessation activities includes five phases: needs assessment, program development, program implementation, program evaluation and program maintenance. It is anticipated that each State participating in PSC will develop a fully operational, Statewide prenatal smoking cessation activity as part of their on-going maternal and child health care delivery system.

Currently, CDC has provided technical assistance in prenatal smoking cessation to Idaho, South Dakota, California and Maine. Plans for FY 1991 and FY 1992 call for the expansion of PSC to a total of approximately 16 additional States over the two year period.

Nutrition Status Assessment and Monitoring

Pediatric Nutrition Surveillance System: Poor nutrition and its effect on childhood morbidity, growth, and development is another important public health issue. There have been few data available on the extent, etiologies and risk factors associated with malnutrition (overnutrition as well as undernutrition) among children. This problem is further complicated by the lack of a satisfactory definition of malnutrition in the domestic setting. The longterm impact of childhood obesity on adult obesity is also not well-defined. Obesity is a particular problem among low income, ethnic minority populations, and the lack of an adequate reference for measuring the condition further complicates the degree to which the problem can be accurately defined. Most of the data currently available on childhood malnutrition and obesity are based on small case studies from which prevalence estimates cannot be made, nor can the determination of risk factors and etiologies.

In 1973, CDC developed a system for the surveillance of nutrition problems (anemia, underweight, overweight, low birthweight) among low income children coordinated through State health departments. Since then, the Pediatric Nutrition Surveillance System (PedNSS) has grown from an initial five States to the present 42 State participants, including the District of Columbia, Puerto Rico, Navajo Nation and other tribal programs. This system primarily uses data from children who participate in the Women, Infants, and Children Supplemental Food Program (WIC) and in other Maternal Child Health Programs which are targeted toward low income

in the Women, Infants, and Children Supplemental Food Program (WIC) and in other Maternal Child Health Programs which are targeted toward low income families. These data provide information to enable States to identify nutrition problems among children who participate in these programs, target interventions and monitor trends.

Lessons learned from a recently completed feasibility project to examine the surveillance of severe pediatric undernutrition will be used to enhance the practical usefulness of the PedNSS in identifying these children. Information on risk factors for children who meet the case definition for severe undernutrition will assist States to promptly initiate early intervention. Successful strategies for detecting severe undernutrition among children in hospitals and other health and social service care facilities will be summarized and disseminated to States.

CENTERS FOR DISEASE CONTROL
OFFICE OF THE DIRECTOR, HUMAN IMMUNODEFICIENCY VIRUS

Infant Mortality

Preventing HIV Infection Among Women and Infants (Pediatric AIDS)

Surveillance for pediatric HIV disease is being conducted through: 1) expanded efforts in national surveillance of HIV infection and AIDS in infants and children, including surveillance for all HIV infection in selected cities and States to better define the extent of the problem in this population; and 2) HIV seroprevalence surveys in neonates in 45 States and in young children attending outpatient clinics in the cities of New York, Washington, and Miami. Ongoing studies in Atlanta, New York, and Newark of children born to HIV-infected mothers are seeking to define risk factors for transmission of HIV from mother to child, evaluate new tests for diagnosis of HIV in infants, and better describe the course of the disease in infants. These children will also enter into treatment trials whenever possible. A study of women of childbearing age in a south Florida community with a high HIV prevalence is evaluating their sexual practices and possible approaches for supporting behavior change that will reduce the risk of infection in these women and their children.

Financial and technical support was provided to assess the behaviors associated with reproductive decision-making among women attending New York area gynecologic, prenatal and family planning clinics.

In addition, Perinatal HIV Prevention Projects have been funded to encourage the effective use of contraception among HIV-infected women and women at high risk of infection who wish to avoid pregnancy. Seven Perinatal AIDS Prevention Projects, totaling over \$5 million, were funded in fiscal year 1990 and will continue to be supported in fiscal year 1991. These projects will: 1) determine and seek to overcome obstacles to effective use of contraception among target populations; 2) facilitate the use of family planning services among the target population; 3) evaluate attitudinal factors related to use of contraception among HIV-infected and high-risk women; 4) encourage behavioral change among HIV-infected and high-risk women to reduce risk of acquisition or transmission of HIV.

Infant MortalityChildhood Immunization

Since 1963, the Centers for Disease Control has provided project grant support, disease surveillance, technical assistance and consultation, immunization level assessment, outbreak control, and other activities to assist State and local health agencies in planning, developing, and conducting childhood immunization programs. In 1991, approximately \$62.5 million was utilized to support immunization-related activities which were targeted toward immunization of children under 12 months of age thereby preventing morbidity and mortality from polio, Haemophilus Influenzae type b (Hib), diphtheria, pertussis, and tetanus in these infants. Measles, mumps, and rubella generally occur in children over 12 months of age except during preschool outbreaks in inner-city populations.

These activities have resulted in dramatic reductions in reported morbidity and mortality of polio, diphtheria, pertussis and tetanus in the Nation's infant population. There has not been an indigenous case of wildvirus polio reported in the United States since 1979. In 1990, no cases of tetanus and only one case of diphtheria was reported in children less than 12 months of age.

In 1990, CDC initiated a perinatal hepatitis B program to prevent hepatitis B morbidity in infants thereby preventing mortality due to hepatitis in adult years. In 1992, it is estimated that this program will identify and immunize approximately 17,800 infants born to hepatitis B-infected carrier mothers.

In October 1990, a Hib vaccine was approved for use in infants, and Congress included \$25.8 million in the 1991 appropriation to provide an estimated 5 million doses of this vaccine to be administered to infants less than 12 months of age. It is estimated that this support coupled with increased use of this vaccine in infants in the private sector will prevent up to 18,000 cases of Hib diseases and prevent as many as 1000 deaths annually from this disease.

CENTER FOR DISEASE CONTROL
CENTER FOR INFECTIOUS DISEASESInfant MortalityInfectious Diseases In Infants

Diarrheal illnesses are the cause of death for about 500 children in the U.S. each year. These deaths are not associated with other severe diseases (e.g., cancer) but are associated with preventable complications of diarrhea including dehydration, electrolyte imbalance and cardiac arrest. Deaths are 5 times more common among blacks than whites, occur with greater frequency in the South than the rest of the country, and are associated with social factors, such as mothers not completing high school, being young and unmarried, and not attending prenatal clinics. These deaths represent 10-15% of the preventable, post-neonatal infant mortality in this country and should be targeted for immediate investigation and interventions.

Measles continues to be a major problem in developing countries. An estimated 70 million cases are reported to occur each year resulting in the deaths of 2 million children, to say nothing of the morbidity caused by the disease. In these settings, the problem is delivering vaccine to infants less than 9 months of age which would narrow the window of susceptibility to infection. However, the vaccine must be able to induce an antibody response and confer immune protection in the presence of maternal antibody.

Transmission of hepatitis B virus (HBV) from mother to infant during the perinatal period represents one of the most efficient modes of infection. In June, 1988 the Immunization Practices Advisory Committee (ACIP) of the U. S. Public Health Service recommended that all pregnant women in the United States be screened for hepatitis B during pregnancy, so that infants born to hepatitis B virus (HBV) carrier mothers could be treated with hepatitis B vaccine and hepatitis B immune globulin (HBIG) to prevent their becoming HBV carriers. Successful screening could detect an estimated 21,993 pregnant hepatitis B carriers, and treatment of infants born to these women would prevent HBV infection in at least 6,535 infants each year. Ultimately, it is estimated that 25% of such infants, if untreated, would eventually die from chronic liver disease (cirrhosis, primary liver cancer) due to HBV infection. The guidelines also stated that, when an HBV carrier mother is identified, all household contacts should be screened and hepatitis B vaccine offered to those who are susceptible.

CENTER FOR DISEASE CONTROL
NATIONAL CENTER FOR HEALTH STATISTICS

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Infant MortalityNCHS Activities

The National Center for Health Statistics (NCHS) obtains data on infant mortality from several sources including the following:

Natality Statistics System: Collects and publishes data on births in the U.S. based on information reported on birth certificates filed during a given year including medical and behavioral risk factors, preventive care, and birthweight.

Mortality Statistics Program: Collects and publishes data on deaths in the United States based on information reported on all death certificates. Provides data on demographic characteristics on infants who die in the first year of life.

Fetal Mortality Statistics Program: Collects and publishes data on fetal deaths in the United States. Provides information on the characteristics of fetal death similar to information on the birth certificate plus medical information on fetal and maternal conditions that contributed to or caused fetal death.

Linked File of Live Birth & Infant Death Records: Used to assess infant mortality in relation to risk characteristics of mother and infant and prenatal care. Greatly enhances the ability to monitor trends and variations in infant health.

National Maternal & Infant Health Survey (NMIHS): The 1988 survey included data from 21,000 mothers designed to study factors related to fetal loss, low birth weight, and infant death. Information collected included data on hospital and prenatal care received. A followup survey will recontact 12,000 mothers and their children's medical providers to obtain updated health histories on mothers and infants.

CENTER FOR DISEASE CONTROL
CENTER FOR ENVIRONMENTAL HEALTH AND INJURY CONTROL

Infant Mortality

Birth Defects

Birth Defects Monitoring Program: Monitors the occurrence of birth defects/congenital anomalies in a national sample of 1,000,000 U.S. births in over 1000 hospitals. Impact: Provides data twice each year on 150 kinds of birth defects among 1/3 of the nations births each year since 1970. Identifies and generates annually reports on 30,000 infants with birth defects. Provides a national early warning system for drugs and environmental agents causing birth defects and for failures in birth defects prevention services. Provides a source of cases for epidemiologic and genetic study.

Metropolitan Atlanta Congenital Defects Program: Maintains an intense, active, local population-based surveillance program. Impact: Provides reliable prevalence data for national use and cases for most of CDC's birth defects epidemiologic studies. Used to train staff and study surveillance methods. Provides basis for technical assistance to State health departments planning or conducting surveillance.

Improvement of FAS surveillance: Improve method of identifying cases of Fetal Alcohol Syndrome (FAS) in existing surveillance systems and data sets by identifying patterns of associated malformations. Impact: Improve accuracy of prevalence data, estimate the degree of under-counting of FAS in current surveillance systems. Provides data to monitor progress toward Year 2000 objectives.

Birth Defects Surveillance Technical Assistance: Provide technical assistance and consultation to States conducting or planning birth defects surveillance systems and develop methods to share data at the national level. Impact: Currently assisting 20 states. Studying ways to make meaningful comparisons of data in order to share this data on a national level.

Accutane embryopathy: Develop improved methods of surveillance of Accutane embryopathy, a very severe and totally preventable birth defect caused by maternal use of the drug Accutane. Impact: Can be used to evaluate the effect of newly instituted control measures on the occurrence of birth defects and mental retardation caused by this drug used to treat acne.

Spina Bifida Vitamin Study: Conducting a randomized clinical trial in China to determine whether or not vitamins taken before pregnancy begins will prevent spina bifida and anecephaly. Impact: A method to prevent spina bifida and anecephaly would reduce infant mortality and reduce the lifelong morbidity of surviving paralyzed infants with spina bifida. On a world-wide scale, vitamin supplementation, if proven to prevent spina bifida and anecephaly, could provide a major improvement in child health equal to the effect of the polio vaccine. In FY91, the pilot program will be implemented.

Birth Defect Risk Factor Surveillance: Determine the factors that may predispose to birth defects from environmental exposures such as drugs or alcohol. Improved laboratory methods available since last study (1980) may make it possible to understand the scientific basis for the fact that exposures cause birth defects for only a relatively small proportion of those exposed. Impact: The ability to know in advance of exposure those individuals for whom exposure is likely to cause birth defects could lead to more effective prevention measures, especially for FAS. Protocols will be developed in FY 91 for a pilot study of risk factors.

Analyze Birth Defect Risk Factor Data: Analysis of existing data to evaluate more than 100 risk factors that are associated with the prevalence of birth defects. Impact: To obtain clues to causes of birth defects. Reports will be written during FY 91 on at least 2 risk factors.

Developmental Disability

FAS/Mental Retardation: Improve surveillance of fetal alcohol syndrome (FAS) and other adverse effects of maternal alcohol use such as mental retardation. Activities will include: develop a local pilot program to detect FAS and other adverse effects of alcohol and offer intervention services to the infants; assist State programs in developing FAS surveillance; assist in coordination of State and Indian Health Services activities upon request. Impact: Improve accuracy of prevalence data and estimate the undercounting in current surveillance systems. Provide an opportunity to monitor effectiveness of prevention/intervention activities.

FAS Prevention Conference: Organize and co-host a national conference on fetal alcohol syndrome to discuss surveillance and prevention/intervention methods. Impact: Provide guidance to States and research scientist interested in surveillance and prevention/intervention of FAS.

Developmental Disabilities Surveillance: Conduct population-based surveillance of developmental disabilities among school-aged children in metro Atlanta. Assist States in conducting similar population-based surveillance. Gather information on which to base a national surveillance system for developmental disabilities. Impact: Have developed methods to determine prevalence of developmental disabilities among 10-year-olds. These methods have the potential to help establish the causes of developmental disabilities. Study has already shown marked association of prevalence of mental retardation and poverty. Will be used to determine risk factors and associations for mental retardation and to track progress toward Year 2000 objective to reduce mental retardation.

Developmental Disabilities Pre-School Surveillance: Planning to develop, with State and local health departments, surveillance for developmental disabilities among pre-school children. Impact: Identifying these children at a very young age allows for more effective intervention programs to minimize the disability. Develop a funding mechanism to establish or improve surveillance for developmental disabilities.

Data Development for Secondary Conditions and Disabilities: Collect population-based, longitudinal data bases containing information on

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conditions which develop secondary to other disabilities, such as skin ulcers and joint contractures in persons who are paralyzed. Impact: Provides information on functional limitations and risk factors for secondary conditions and leads to better understanding of natural progression and causes of secondary conditions. Provides data to use in developing prevention/intervention programs and to evaluate the outcome of these programs.

Developmental Disabilities Risk Factors: Analyze data from the Metropolitan Atlanta Developmental Disabilities Study to: assess the contribution of known causes of mental retardation to determine the prevention gap by specific causes of mental retardation; study possible association between maternal occupations and mental retardation; examine the relationship between socioeconomic factors and mental retardation; and examine the relationship between maternal alcohol use and mental retardation. Impact: Provide scientific data that describe the relative and attributable risk for various factors associated with or causing mental retardation and other developmental disabilities. Two reports on risk factors will be issued in FY91.

Infant MortalityInjury Control

The CDC Injury Control Program conducts a number of activities that focus on the prevention of infant mortality. First, the Injury Control program provides leadership in efforts to prevent injuries to children and infants through its participation in the Secretary's Interagency Task Force on Child Abuse and Neglect. Second, the program funds research, surveillance, intervention and evaluation projects at a variety of public and private institutions including State and local health agencies. These projects are aimed at the prevention of injuries to all age groups including infants. Third, the injury control program developed a major report for Congress on childhood injuries which included information on the incidence and prevalence of fatal injury to infants. Lastly, the program conducts intramural research studies that also focus on the problem of fatal injuries to children including infants.

CENTER FOR DISEASE CONTROL
CENTER FOR ENVIRONMENTAL HEALTH AND INJURY CONTROL

Infant Mortality

Lead Poisoning Prevention in Infants

CDC's efforts in the area of infant mortality include the following:

The Lead Poisoning Prevention In Infants program is an ongoing program to conduct a variety of State and community-based program support and capacity building projects that include financial and direct assistance, on-site technical and management assistance and consultation, surveillance activities, epidemiologic studies, and proficiency testing and reference laboratory services to eliminate the problem of infant and childhood lead poisoning in selected high-risk communities.

Ongoing activities include developing a national surveillance system for elevated blood lead levels to identify which parts of the country have the greatest problems, and to track progress towards eliminating infant and childhood lead poisoning. Financial and technical support are provided to intensify and to improve screening and case management programs, and to support training and educational activities directed to health care professionals and to communities.

In FY 1990, grants were awarded to six States and one metropolitan health department to develop, to improve, or to expand childhood lead poisoning screening and follow-up programs. In the same year, grants were awarded to five State health departments to enhance surveillance of lead poisoning.

An estimated 90,000 children will be screened by programs that were funded in FY 1990. In FY 1991, up to six additional grants will be awarded for screening and follow-up programs. Additionally, up to three State or community-based health agencies will receive financial assistance to evaluate the effectiveness of lead paint abatement.

In future years, as a result of CDC supported program activities, there will be a substantial increase in the number of children receiving early intervention to reduce lead exposure.

HEALTH RESOURCES AND SERVICES ADMINISTRATION
Bureau of Health Care Delivery and Assistance

INFANT MORTALITY

As a part of their overall clinical services, the BHCDA health care delivery programs make comprehensive perinatal care services available to pregnant women in underserved areas with high infant mortality rates.

These services to improve the pregnancy outcomes and health status of underserved women and infants encompass: (1) systems of care designed to incorporate case management into the delivery model and enhance health services that are responsive to the medical, social, and behavioral needs of pregnant women and infants; (2) maintenance of current perinatal capacity within C/MHCs through efforts to retain or recruit obstetrical health care providers to include, among other, obstetrician/gynecological and family practice physicians and certified nurse midwives; and (3) expansion of capacity to evaluate progress of current and expanded perinatal interventions based on health outcomes and health status (i.e. measures such as low birth weight teenage pregnancy rates, and infant mortality).

In order to enhance case management activities, and in turn maximize positive birth outcome, support is provided for patient education and outreach. Case management activities include, but are not limited to: casefinding; reducing nonfinancial barriers to care, such as translation assistance; reducing financial barriers through assistance in enrollment in Medicaid; and providing patient education regarding related medical and health services, assistance and resources that are available in community (AFDC, WIC, EPSDT, and housing), and how to gain access to them.

In FY 1991 the increase in C/MHC funds over the FY 1990 level will be directed at those areas that are experiencing the highest rates of infant mortality. Emphasis will be placed on getting pregnant women into prenatal care and improving health outcomes by ensuring availability of case-managed services at new and existing centers and sites. This perinatal care program will target funds and efforts towards keeping the babies that are delivered in well-child care long enough and continuously enough that they obtain needed immunizations and other preventive health care services. The capacity of these programs to serve additional women in need will also be enhanced.

Another BHCDA program, Health Services in Underserved Neighborhoods will improve access to and support the delivery of ambulatory health and social services in clinics at or in close proximity to public housing, in some cases supported by HUD financing. This program directs a significant portion of their services to public housing residents for case-managed infant mortality prevention.

HEALTH RESOURCES AND SERVICES ADMINISTRATION
Bureau of Health Professions

Infant Mortality

In response to the pressing need to slow the rate of infant deaths nationwide, the Bureau supports some training initiatives focusing on the clinical training and patient education aspects of sudden infant death syndrome.

In FY 1990, the Advanced Nursing Education Program awarded ten grants totaling \$1,448,468 designed to prepare master's and doctoral level nurses to address the problems of mothers and children in acute care and other settings. Preparation of teachers and researchers in this important area also occurs in these educational programs.

The Nurse Practitioner and Nurse Midwifery Program awarded \$6,059,033 to 36 projects to support preparation of nurses who are able to serve as nurse midwives, obstetrical and gynecological practitioners, and pediatric practitioners. In all cases, these nurses focus on patient teaching, guidance, counseling and health screening activities.

Public health funds have been used to support traineeships to improve administration and competency of personnel in maternal and child health programs. In FY 1990, \$187,241 was awarded for traineeship support in maternal and child health.

An estimated 115,267 individuals benefitted from the Area Health Education Center programs targeted for training in maternal and child health. A total of \$382,850 was awarded among 9 of the 13 grantees reporting activities in this area.

Under the new Health Education and Training Centers program, two grantees have indicated that they will develop training components covering issues related to maternal and child health. The University of California, Davis, received \$150,000 for their efforts to train an estimated 100 individuals through their Border project.

A total of \$212,451 was awarded to nine of 38 Physician Assistant Training programs which indicated maternal and child health care activities. It is estimated that 1,968 trainees will have educational experience in this area. The University of Colorado Child Health Associate Program for training physician assistants received \$165,000 for development of an entire curriculum in child health (prenatal through adolescence).

Three of the section 786(a) Family Medicine Predoctoral program grantees indicated educational emphasis in areas affecting the health of women and children, particularly with regard to developing OB/Gyn electives. Brown University received \$69,400 for its programming in the area of maternal and child health.

Fourteen Graduate Training program grantees indicated activities to improve OB/Gyn and neonatal curriculum and training experiences for 13 residents. Three of the grantees received a total of \$105,330 for these initiatives.

One grantee under the section 788(c) Preventive Medicine Residency Training program reported training experience in the area of maternal and child health. No specific funds were requested for their efforts.

Maternal and child health issues related to HIV/AIDS are covered in the training offered by one AIDS Regional Education and Training Centers program grantee.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Maternal and Child Health Bureau

Infant Mortality

The Maternal and Child Health Bureau (MCHB) was established to strengthen the Federal effort toward meeting the special health care and related needs of mothers, infants, children, and adolescents in our society, and especially toward reducing this country's unacceptably high infant mortality rate. MCHB administers three programs which impact on reducing infant mortality. MCH staff provide technical assistance to the States to formulate plans to address the Year 2000 objectives for infant mortality.

The Maternal and Child Health Block grant awards funds to States to enable each State to provide and to assure mothers and children access to quality maternal and child health services. One of the emphasis of the program is to reduce infant mortality and the incidence of preventable diseases and handicapping conditions among children. Although firm data is not yet available on state activities it is estimated that 30% of the State allocations are targeted to infant mortality.

The Significant Projects of Regional and National Significance (SPRANS), authorized as a 15 percent set-aside of the Maternal and Child Health Block grant, addresses infant mortality and low birth weight in several ways. Projects are funded which address various methodologies to improve the utilization and content of prenatal care, risk appropriate care, reduction of behavioral risks, care coordination and local Infant Mortality reviews. Research projects support examination of issues and factors directly concerned with or related to infant mortality. Funds have also supported a number of local/state efforts at problem identification, analysis, and evaluation. Efforts have also been directed to improve public/private coordination and collaboration as well as public/professional communication and education. The development of the Maternal and Child Health handbook was initiated with SPRANS funds. SPRANS funds will be used to continue this activity. The MCHB has funded two one stop shopping projects with SPRANS awards to enhance access to prenatal and postnatal care and related services. These projects will be continued and additional projects will be undertaken in FY 1991 and FY 1992. The Bureau has also funded projects to gather data on infant mortality and services available in States. In implementing the provisions of the Omnibus Budget Reconciliation Act of 1989 the Bureau will work with States and private organizations to establish complete and consistent data on prenatal and infant health and the provision of prenatal and infant health care in the States.

The Emergency Medical Services (EMS) for Children Program was

created to enhance and expand delivery of EMS for acutely ill and seriously injured children and recognized that the needs of such children tend to be different from those of adults and are often not being met by the current EMS systems either during the pre-hospital or in-hospital phases.

The Pediatric AIDS Health Care Demonstration program is designed to demonstrate effective ways to prevent infection, especially through the reduction of perinatal transmission; develop community based family centered, coordinated services for infected infants; and develop programs to reduce the spread of HIV infection to vulnerable populations of young people.

INDIAN HEALTH SERVICE

Infant Mortality

The reduction of infant mortality among American Indians and Alaska Natives (AI/AN) is an important objective of the Indian Health Service (IHS). Through direct and contract programs, prenatal, perinatal, neonatal and post-neonatal care, are provided to mothers and infants. Community based indigenous health workers, primary care professionals, and secondary and tertiary based specialists work together in a regionalized system to provide this comprehensive care.

Maternal and Child Health is not an IHS line item. However, based on the numbers of deliveries, newborns, infant care, prenatal care and certain specific prevention programs (Alaska Prenatal initiative, Haemophilus influenzae prevention and FAS prevention) cost estimates can be derived. The IHS expended an estimated \$212,147,000 in Infant Mortality prevention in FY 1990. Since IHS program activities are primarily rural, the difficulty and cost of delivering a reasonably high technical level of health care increases.

The latest (FY 1986) AI/AN infant mortality generally was 9.8 deaths per 1000 live births. This is a 48 percent decrease since 1974 and is 0.9 times the rate for U.S. All Races. Data from IHS Service Areas show an average infant mortality rate of 11.2. A more detailed analysis of this data show two important facts: (1) AI/AN infants are at a higher risk from 28 days to 11 months of age, and (2), ten of the 12 IHS Areas have infant mortality rates above the rate for U.S. All Races.

Efforts to reduce infant mortality must target high risk population subsets. Therefore, program activities to reduce infant mortality in the future will be strengthened to focus on the following:

1. Adolescent pregnancy rate (currently 20 percent of AI/AN births are to mothers less than 20 years of age)
2. Fetal alcohol syndrome rate (data gathered from some areas show rates from 6 to 10 per 1000 live births)
3. Sudden Infant Death Syndrome (SIDS) (in regions of high infant mortality the post-neonatal deaths due to SIDS is very high)
4. Prenatal care (significant high risk population subsets do not participate in prenatal care)

NATIONAL INSTITUTES OF HEALTH

National Institute of Child Health and Human Development

INFANT MORTALITY

More than a decade ago, the Federal Government set a goal for the Nation: to reduce the infant mortality rate to no more than 9 deaths per 1,000 live births by 1990. By the end of 1989, the provisional infant mortality rate had dropped to 9.7 deaths per 1,000 live births--the lowest U.S. level ever recorded, but still higher than the government's goal.

The infant mortality rate is defined as the number of deaths of children younger than one year old per 1,000 live births in a given year. Paradoxically, the United States has a higher infant mortality rate than many other developed countries, while at the same time spending billions of dollars annually on medical care. It also has some of the most technologically advanced hospitals, medical equipment and neonatal intensive care units in the world. Yet in 1986, the last year for which final infant mortality rates were available, 21 countries had lower infant mortality rates than the United States including Japan, at 5.2; Finland, 5.9; Sweden, 5.9; Switzerland, 6.8; Hong Kong, 7.7; The Netherlands, 7.8; Canada, 7.9; Norway, 8.0; France, 8.0; and Denmark, 8.2. The 1986 infant mortality rate for the United States was 10.4.

The infant mortality rate is affected by a number of different variables, including prenatal care; maternal nutrition; cigarette, drug and alcohol abuse; premature birth; intrauterine growth retardation resulting in low birth weight (less than 5 1/2 pounds or 2,500 grams); and certain birth defects. Another contributor to infant mortality is Sudden Infant Death Syndrome (SIDS), the causes of which still remain relatively mysterious.

Recognizing the urgent need to reduce infant mortality in this country, the National Institute of Child Health and Human Development (NICHD) leads the infant mortality research effort for the National Institutes of Health (NIH). Other institutes that conduct or support studies related to infant mortality are the National Heart, Lung and Blood Institute (NHLBI); the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); the National Institute of Neurological Disorders and Stroke (NINDS); the National Institute of Allergy and Infectious Diseases (NIAID); the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); the National Center for Research Resources (NCRR); and the National Center for Nursing Research (NCNR); and the Office of the Director, NIH.

Studies Seek Answers to Causes of Birth Defects

Birth defects are the leading cause of infant mortality. NICHD supports an intensive research program in early fetal development, emphasizing the genetic control of this process. As part of this research, studies are being conducted to better understand DNA and its role in birth defects. Unrepaired lesions in DNA can result in mutations, including those that cause genetic diseases, birth defects, and probably cancer. These lesions can be caused by a wide variety of carcinogens and mutagens, including ultraviolet (UV) radiation (sunlight).

A team of NICHD intramural scientists headed by Dr. Arthur Levine has discovered a novel protein, produced in primate cells in response to DNA damage by UV, that recognizes and binds specifically to sites of UV damage. This protein, known as "DDB", is the first such damage-specific, damage-inducible DNA-binding protein identified in primate cells. DDB is defective in at least some patients with xeroderma pigmentosa, a genetic disease characterized by sun sensitivity and increased risk of cancer. It is possible that other cancers and genetic diseases also may result from defective DDB.

In the mechanism of DDB repair, it is likely that after DDB recognizes and binds to sites of UV damage in DNA, this becomes the site of a repair process involving enzymes that excise the damage and insert the correct nucleotides (DNA chemical subunits) at the site of the lesion.

Mouse Model Facilitates Research on Abnormal Development

The mouse is a useful animal model for investigating the bases of abnormal development, which can result in congenital defects. This research traditionally involves studying developmental mutants (damaged or altered organisms) either by classical genetic approaches or analysis of embryo development in laboratory cultures. One difficulty with current methods of generating mouse developmental mutants, however, is that it is impossible to know in advance if the foreign DNA inserted into the mouse model will be inactivated or expressed (direct the production of a protein). Dr. Mario Capecchi of the University of Utah in Salt Lake City and Dr. Franklin Costantini of Columbia University in New York have overcome this difficulty by inserting a modified piece of DNA, or gene, into mouse embryonic stem (ES) cells grown in tissue culture. These cells are then placed into mouse embryos and the new DNA is incorporated into all the cells of the resultant animals.

ES cells can now be used with a technique known as homologous recombination. This technique makes it possible to target foreign DNA to a specific location in a host's DNA so that a specific piece of DNA, or gene, in an animal can be replaced with an altered form of that same gene. Thus, it is now theoretically possible to use ES cells and homologous

recombination to generate mouse models for any genetic disease for which the causative gene is known and isolated.

Sudden Infant Death Syndrome Remains a Mystery

SIDS, also known as crib death, has long perplexed scientists. The leading cause of death in U.S. children age 1 to 12 months, SIDS now causes approximately 5,000 to 6,000 infant deaths annually. Most of these apparently normal babies succumb to SIDS when they are between 2 and 4 months old.

In June 1989, a group of scientists met at NICHD and formulated a new definition of SIDS to apply to future research studies: The sudden death of an infant under one year of age, which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history.

While the exact cause of SIDS remains unknown, researchers have ruled out certain conditions that at one time were thought to play a role. These include choking, parental neglect and allergy. Today, NICHD-supported scientists are taking three main approaches to SIDS research: 1) pathological and physiological studies; 2) research on the clinical manifestations, and 3) development of animal models.

Scientists Study Infant Sleeping Patterns

Current pathological and physiological theories indicate that SIDS victims may have difficulty coordinating heart rate and breathing during sleep. Accordingly, NICHD-funded scientists are performing autopsy studies of SIDS victims, paying special attention to the parts of the nervous system that control heart and respiratory function.

NICHD-supported research by Dr. Vicki Schechtman at the Brain Research Institute at the University of California, Los Angeles, has found that differences in the number of short pauses in breathing (apnea) during sleep may be a clue as to why apparently healthy babies die of SIDS. After the age of 1 month, infants who subsequently died of SIDS showed fewer pauses in breathing than infants who did not die. At less than 1 month of age, SIDS infants and other infants showed similar breathing patterns. This new finding suggests that SIDS may be caused by the failure to recover from normal pauses in breathing and not from an increased likelihood of having a breathing pause.

Under a new grant funded this year, Dr. Ronald Ariagno of Stanford University in California is studying the development of sleep and arousal patterns of babies in neonatal intensive care units (NICUs) in association with day and night--circadian--rhythm. The development of this type of rhythmical organization is critical to the regulation of physiological functions during sleep. Dr. Ariagno is studying these processes in the babies

while they are in the NICU and after they have been discharged. Because standard NICUs are constantly lighted, he also is investigating the effects of providing a controlled light/dark stimulus in the NICU, similar to the light/dark patterns in the home, on the maturation of the babies' physiological functions.

Role of Food Poisoning in SIDS Explored

Infant botulism or related intestinal infections may be the cause of a relatively small number of SIDS deaths. NICHD continues to support research into the role of potential infectious organisms, specifically Clostridium perfringens, a microorganism that produces a highly toxic substance, or enterotoxin, that causes food poisoning. This substance causes sudden death in infant mice, but not in adult mice. Investigators in a study led by Dr. James Lindsay at the University of Florida in Gainesville hope to clarify the interaction between the toxin and the gastrointestinal system of infant mice. In addition, they will examine fecal specimens of SIDS victims for the presence of enterotoxin.

Studies Seek to Identify Risk Factors for SIDS

Last year, a SIDS Histopathology Atlas was completed by NICHD's Howard Hoffman. Included in the atlas are the results of microscopic and quantitative analyses of tissue specimens from NICHD's Collaborative SIDS Epidemiologic Study. This study of approximately 800 SIDS victims, 1,600 living infants, and their families was initiated 10 years ago to help develop a profile of infants at risk for SIDS.

A major impediment in the study of SIDS is that scientists are unable to determine which babies are at risk of succumbing to sudden infant death. While some babies--premature infants, for example--can be identified as being at higher risk, this is not a foolproof way of identifying likely SIDS victims. Accordingly, Dr. Steven M. Pincus of Chaotic Dynamical Systems in Guilford, Connecticut is developing a mathematical formula to analyze heartbeat data from high-risk infants. By applying the formula first to normal babies, and then to babies who are at risk, investigators hope to determine which babies are at risk of later dying of SIDS.

In the search for characteristics of infants at risk for SIDS, animal models also are being used. Dr. Jim Fewell at the University of Calgary in Alberta, Canada is looking at how different amounts of oxygen and carbon dioxide in the blood affect the sleep arousal response in lambs. He has found that proper functioning of the carotid body, a small chemosensory organ that helps regulate respiration, is critical for the lamb to arouse itself from sleep in response to low blood oxygen (hypoxemia). Because the structure and chemical composition of this organ in SIDS victims have been found to be abnormal, this study may help clarify vulnerability in human infants.

In addition, Dr. Fewell and his colleagues have established that when lambs are repeatedly exposed to a lack of oxygen, their arousal response to hypoxemia is reduced. Since other studies have suggested that SIDS victims suffer chronic oxygen deprivation, this finding may help clarify why some infants are at greater risk for SIDS during sleep.

Intrauterine Growth Retardation Factors Assessed

In most previous studies, the two best predictors of intrauterine growth retardation (IUGR) have been found to be small maternal size and cigarette smoking during pregnancy. Yet even when combined with other characteristics associated with IUGR, these two factors account for fewer than half of all IUGR cases.

In an effort to identify a sub-population at greater risk for IUGR, NICHD is collaborating in a large, prospective multinational study with Dr. Robert Goldenberg at the University of Alabama in Birmingham and Dr. Leiv Bakkeiteig at the University of Trondheim in Norway. Other sites in Scandinavia include the University of Bergen in Norway and the University of Uppsala in Sweden. This study, which is designed to explore the relationship between IUGR and various psychosocial factors such as social support, nutrition and lifestyle, has shown that heavier women seem to be better protected against the adverse effects on fetal growth of a poor psychosocial profile and cigarette smoking. Both of these factors have a major adverse effect in thin women. When smoking and a poor psychosocial profile are not present, however, thin women have as low a rate of IUGR as heavier women.

Child Health Research Centers Established

This year, NICHD initiated a new national program of seven research centers designed to accelerate the application of findings from basic science to the care of sick children. Each of these centers will concentrate on a particular area of pediatric research. Investigators from a variety of scientific backgrounds will combine their efforts and will work with newly trained pediatricians to establish "centers of excellence" in the chosen subject areas.

Physically Demanding Jobs Have Little Outcome on Pregnancy

Strenuous, stressful work during pregnancy has long been implicated in adverse pregnancy outcomes. But a large number of the women in physically demanding jobs are of low socioeconomic status and few studies have been able to determine whether adverse pregnancy outcomes are due to the work itself or a low socioeconomic status.

To clarify the interrelationship between work, socioeconomic status and pregnancy outcome, NICHD's Drs. Mark A. Klebanoff,

Patricia H. Shiono and George G. Rhoads conducted a survey comparing pregnancy outcomes between female medical residents and the wives of medical residents. Both groups are highly educated and enjoy a relatively high standard of living; thus, the investigators were able to eliminate low socioeconomic status as a confounding variable. They found no significant differences between the two groups in terms of number of miscarriages, ectopic (fallopian tube) gestations, and stillbirths. These results indicate that long working hours and physically demanding occupations have little impact on pregnancy outcome in healthy women of high socioeconomic status.

National Cancer Institute

For the past five years, the National Cancer Institute has funded a model program designed to prevent smoking among pregnant women in order to reduce the number of low-birth-weight infants (LBW) born each year. The Surgeon General has deemed smoking cessation among pregnant women a top priority.

In 1990, 4 million infants were born in the United States. Of those, 6.8 percent, or a quarter of a million children, were LBW infants. Numerous studies have shown that maternal smoking is a principal cause of LBW, and LBW is a primary cause of infant mortality. Epidemiologic studies confirm that the range of smoking-attributable risk for LBW is 20 percent to 35 percent. Of the 36,000 infant deaths, two-thirds are born with low birth weights.

Smoking Cessation Programs

Dr. Richard Windsor and colleagues at the University of Alabama's Comprehensive Cancer Center in Birmingham have been studying the effects of smoking cessation techniques among low-income women in four Birmingham clinics.*

The purpose of this trial was to develop a multi-component smoking cessation program and to determine its impact in reducing the number of women who smoke. In this study, Dr. Windsor evaluated 1,000 pregnant smokers, with 500 women randomly assigned to receive intervention and 500 randomly assigned to a control group. Personal monitoring and testing for nicotine metabolites in the saliva were done at six different times to document behavioral changes.

Dr. Windsor's studies have shown that low birth weight might be prevented in 2,200 infants each year by using proven smoking cessation methods. The cost to provide these methods would be minimal--approximately \$1.7 million a year. In contrast, the cost of treating LBW infants is approximately \$33 million per year (an estimated \$15,000 per infant).

Nationwide application of efficacious smoking cessation programs among those women who may become mothers and who use public health/prenatal care facilities could result in 280,000 fewer smokers and 22,000 fewer LBW infants by the year 2000. For women who do not use public health/prenatal care facilities, the positive effects during a 10-year period would be even higher, with 840,000 fewer smokers and 50,400 fewer smoking-attributable LBW infants by the year 2000. Thus, with the use of smoking cessation programs geared toward pregnant women, more than

1. *Richard Windsor, Ph.D., M.P.H.--Handbook to plan, manage and evaluate smoking cessation in pregnant women. (Published December 1990 by the March of Dimes, New York, N.Y.)
1 million women might quit smoking and prevent more than 70,000 newborns from being born with LBW by the year 2000.

National Heart, Lung, and Blood Institute

The National Heart, Lung, and Blood Institute supports research in heart, lung, and blood disorders that may lead to death in both premature and full-term infants.

FDA Approves Synthetic Surfactant

After five years of clinical trials, the Food and Drug Administration (FDA) has approved a new drug, Exosurf, for the treatment of respiratory distress syndrome (RDS). This breathing disorder, which causes disability and death in thousands of premature infants annually, occurs when the lungs of premature infants are unable to make surfactant, a substance that helps the lungs inflate easily and prevents them from collapsing during expiration.

Exosurf is a synthetic surfactant developed by Dr. John Clements and colleagues at the University of California, San Francisco; it was tested in a clinical trial supported by an NHLBI Specialized Center of Research (SCOR) grant to Dr. William Tooley, also at the University of California, San Francisco.

Oxygen Administration May Cause Bronchopulmonary Dysplasia (BPD) in the Premature Newborn

Numerous animal studies strongly suggest that administration of high concentrations of oxygen to premature infants may be involved in a variety of acute lung injuries, including bronchopulmonary dysplasia (BPD), a serious, chronic lung disorder of premature infants.

Using new molecular approaches to address this problem, Dr. Lee Frank, an NHLBI grantee at the University of Miami, has shown for the first time that prematurely delivered rabbits fail to produce antioxidant enzymes in the lungs during high oxygen exposure and demonstrate greater oxygen toxicity than do full-term newborn rabbits. These findings may help to explain the high incidence of BPD, which occurs in premature infants exposed to high concentrations of oxygen.

Gamma Globulin Effective in Treating Kawasaki Disease

Kawasaki disease is an acute blood or lymph vessel inflammation of unknown cause that occurs predominantly in infancy and early childhood. First described in Japan in 1967, the disease occurs in both endemic and community-wide epidemic forms in North America, Europe, and Asia, in children of all races. Coronary artery aneurysms or distentions (dilated or enlarged sections of the wall of an artery) develop in about 15 to 20 percent of children with Kawasaki disease and may lead to heart attack, sudden death, or chronic coronary artery

insufficiency. In the United States, Kawasaki disease is a leading cause of acquired heart disease in children.

Earlier data from Japan had suggested that intravenous administration of gamma globulin during the acute phase of Kawasaki disease may decrease the prevalence of coronary artery abnormalities. Therefore, Dr. Fred Rosen and colleagues at Boston Children's Hospital started an NHLBI-supported clinical study to compare the efficacy of intravenous gamma globulin plus aspirin with that of aspirin alone (the conventional therapy) in reducing the frequency of coronary artery abnormalities in children with acute Kawasaki disease. Two weeks after patient enrollment, coronary artery abnormalities showed a three-fold reduction in prevalence among the children receiving gamma globulin. By seven weeks after enrollment, children treated with gamma globulin plus aspirin were five times less likely to show coronary artery abnormalities than those treated with aspirin alone. Gamma globulin also significantly reduced the fever and generalized inflammation characteristic of acute Kawasaki disease.

Early mortality from Kawasaki disease was about 2 percent in the 1970s; with improvements in therapy, primarily the regimen of gamma globulin plus aspirin, early mortality has now fallen to about 0.2 percent. NHLBI-supported research continues at seven U.S. clinical centers to determine the most efficacious way of administering the gamma globulin to reduce mortality further and to improve the quality of life of those affected.

National Institute of Diabetes and Digestive
and Kidney Diseases

Zinc Supplementation in Low-Growth Infants

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) research related to infant mortality and low birth weight focuses on the nutrition factors influencing infant health. Research over the past decade suggests that mild zinc deficiency is one reason that some children do not grow normally for their ages. Scientists have hypothesized that these children may have suffered zinc deficiency in infancy, which contributed to nutritional failure to thrive.

In recent research, NIDDK grantee Dr. K. Michael Hambidge and his colleagues at the University of Colorado Health Sciences Center, Denver, conducted a double-blind, randomized, controlled study of dietary zinc supplementation in 25 pairs of infants and toddlers over a period of 6 months. The subjects were matched for sex, age, weight, and ethnic origin, and the first member of each pair was randomly assigned to receive either zinc supplementation or placebo. Children with malabsorption, chronic infections, or other known causes of growth failure were excluded from the study.

Anthropometric data (weight and length) were collected at 0, 1, 3, and 6 months. Participating parents were taught to keep food records of the children's food intake, and nutrient consumption was analyzed by a nutritionist and by computer with a data base for energy and 12 nutrients. The test children received zinc sulfate in cherry syrup, while the control group received syrup alone.

The researchers found that the children who received zinc supplementation showed significant improvements in weight gain compared to the control group. These results appear to indicate a preexisting, growth-limiting zinc deficiency state that was at least partially corrected by zinc supplementation. The investigators conclude that mild zinc deficiency may complicate and prolong growth problems in some infants with nutritional failure to thrive. They also recommend that pediatricians consider testing underweight infants for zinc deficiency. Further studies of zinc status in pregnant women, infants, toddlers, and in young growth-retarded children with bronchopulmonary dysplasia are under way.

National Institute of Neurological Disorders and Stroke

Approximately 1 of every 1,000 babies born each year suffers from anencephaly, a fatal malformation in which much of the brain is absent. The National Institute of Neurological Disorders and Stroke (NINDS) supports research on anencephaly, with the ultimate goal of preventing this deadly birth defect.

Recent research by NINDS grantee Dr. Aubrey Milunsky at Boston University in Massachusetts shows that women who take multivitamins containing folic acid early in pregnancy greatly reduce their child's risk of neural tube defects, including anencephaly. Anencephaly and spina bifida, which often causes paralysis, are the most common forms of neural tube defect. These disorders arise early in fetal development when formation of the brain or spinal cord goes awry. In the study, Dr. Milunsky followed 22,776 pregnancies, recording such information as multivitamin use, diet, and pregnancy outcome. For women who took folic acid-containing multivitamins during the first 6 weeks of pregnancy, the prevalence of neural tube defects was 0.9 per 1,000 births. But in women who did not take vitamins during this period, the prevalence was 3.5 per 1,000 births. Dr. Milunsky also found that among women with a family history of neural tube defects, the risk of having a child with these defects was higher for those who did not take vitamin supplements (13.0 per 1000 births) compared with those who did (3.5 per 1000). According to Dr. Milunsky, these findings suggest that both genetic predisposition and nutritional deficiency contribute to neural tube defects. Studies such as this are stimulating interest in the role of nutrition in neural tube deformation.

National Institute of Allergy and Infectious Diseases

With the advent of genetic engineering and the resulting availability of numerous potential vaccines, health planners should soon be able to focus more attention on disease prevention. This shift is emerging in part because of research efforts by the National Institute of Allergy and Infectious Diseases (NIAID).

In countries where health care is not immediately accessible, prevention is the only medical option. Such is the case in developing countries, where the severe diarrhea and vomiting of gastroenteritis is the leading cause of pediatric mortality. Worldwide, the major known cause of diarrhea-related deaths in infants is rotavirus infection, which primarily affects children 6 months to 3 years of age.

NIAID intramural scientist Dr. Albert Z. Kapikian and his co-workers are continuing their work with candidate rotavirus vaccines. Developing a rotavirus vaccine is complicated by the fact that there are at least four different rotavirus strains, and recent studies indicate that the ultimate vaccine should contain genes coding for all four types.

Recently, they collaborated with researchers at Vanderbilt University, in Nashville, Tennessee, to evaluate a vaccine that combined a human type-1 strain of rotavirus, designated D, and an animal strain, rhesus rotavirus (RRV).

The investigators vaccinated 26 children in a day-care center and compared their responses with those of five children given placebo. Because a transient fever in some vaccines was the only side effect that developed, the vaccine was deemed safe. Based on extensive testing of blood and stool samples taken at regular intervals after vaccination, the researchers found that, in the infants in the study, the combination vaccine was both infective and antigenic; that is, it elicited an immune response.

Another intramural scientist, Dr. Jorge Flores, has recently completed a study of a potential vaccine derived from another human type-1 strain, M37. M37 is viewed as a potentially valuable vaccine component for two reasons: 1) while it does infect newborns, it rarely causes symptoms; and 2) there is evidence that newborns infected with neonatal strains like M37 are resistant to subsequent rotavirus infection.

Dr. Flores evaluated the oral M37 vaccine in a study involving 90 Venezuelan infants aged 10 to 20 weeks. The follow-up examinations verified that the vaccine was safe, and laboratory tests showed that it had induced antibodies in the majority of infants, an important hurdle to overcome in the development of a vaccine.

These studies provide encouraging evidence that a vaccine formulated with a human strain of rotavirus may be effective in protecting infants against the severe illness caused by rotavirus infection.

National Eye Institute

Retinopathy of prematurity (ROP) is a potentially blinding retinal disease for which premature, low-birth-weight infants are at high risk. ROP affects the developing blood vessels of the retina, the light-sensing tissue at the back of the eye, causing them to grow and branch excessively, leading to bleeding, scarring or retinal detachment. Each year, ROP causes vision loss in an estimated 2,600 American infants.

In April 1988, the Cryotherapy for Retinopathy of Prematurity clinical trial reported its preliminary findings on the use of cryotherapy, a tissue freezing technique, to stop the growth of the abnormal retinal vessels. The study found that cryotherapy reduced the chances of disease progression from 48 percent in untreated eyes to 26 percent in treated eyes.

Although no major complications occurred during or after treatment, monitoring these infants will be essential to evaluate the procedure's long-term safety and efficacy. For this reason, the NEI has recently funded a five-year follow-up study of the infants enrolled in this trial to correlate the structural changes observed in ROP's different phases with the eventual visual capabilities of the eye.

National Institute of Environmental Health Sciences

Developing fetuses and infants are often particularly sensitive to environmental chemicals and agents. The National Institute of Environmental Health Sciences (NIEHS) funds and conducts research investigating many classes of chemicals for their potential perinatal toxic effects such as delayed mental development and teratogenesis (production of physical defects on the embryo).

Toxic Effects of Metals Studied

Metals are often toxic perinatally. NIEHS grantee Dr. Richard K. Miller of the University of Rochester in New York is investigating the toxicity of the metal cadmium in human and rat placental tissue. Cadmium is a contaminant in cigarette smoke. Dr. Miller is using a placental tissue model to determine if other metals that are non-toxic can induce production of a protein (metallothionein) that binds metals and then be used to prevent cadmium toxicity. These studies may be critically important in helping to prevent the occurrence of low birth weight in infants whose mothers smoke.

Another toxic metal with severe health effects is lead. Dr. Joseph Graziano at Columbia University in New York City is conducting an epidemiologic study in a community surrounding a lead smelter in Yugoslavia. Pregnant women in this community have three times the mean blood lead levels of pregnant women in another community at a distance from the smelter. This study seeks to determine whether exposure to lead is associated with an increased risk of spontaneous abortion, stillbirth, premature delivery, intrauterine growth retardation, and congenital malformations.

Mechanisms By Which Chemicals Produce Birth Defects

Using a rat embryo culture system, NIEHS grantee Dr. Mont R. Juchau of the University of Washington in Seattle is studying how toxic chemicals are activated in a fetus to cause damage. His research indicates that embryonic enzyme systems convert chemicals to toxic intermediates in sufficient quantities to produce birth defects.

Dr. Philip M. Iannaccone at Northwestern University Medical School in Chicago, Illinois, is studying the effects of mutagens--agents that induce genetic mutations--on poor pregnancy outcomes in mice. He has established that pre-implantation exposure of blastocysts to certain chemicals can cause reductions in implantation and live birth rates. Chemically exposed blastocysts were found to develop into fetuses with growth retardation and gross deformities. Dr. Iannaccone also is working on strategies using steroid treatment to block bioactivation of toxic chemicals and thus prevent adverse effects

National Institute of Arthritis and Musculoskeletal
and Skin Diseases

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) supports research on a number of diseases that are potentially lethal to infants. These diseases include osteogenesis imperfecta, a brittle bone disease; and ichthyosis and epidermolysis bullosa, serious inherited skin disorders.

Researchers Improve Care for Patients with Epidermolysis Bullosa

Epidermolysis bullosa (EB) is a devastating disease in most forms of which the skin is so fragile that even the slightest injury causes it to break down as if it had been burnt. Patients often have open wounds that become infected and require hospitalization. In a study at The Rockefeller University in New York City, Dr. D. Martin Carter and his colleagues have found that the antibiotic ointment mupirocin controlled infection and promoted wound healing in 47 EB patients. Mupirocin-resistant Staphylococcus aureus (a type of bacteria) developed in five patients, but these organisms were eradicated by oral antibiotic therapy. This work is supported by grants from the NIAMS and the National Center for Research Resources.

In dystrophic EB, deep blisters form when a split occurs in the dermis, which lies beneath the outer layer of skin called the epidermis. In these disorders, structures called anchoring fibrils are diminished or absent. These structures, composed of collagen VII, normally weld the dermis to the epidermis. Researchers have speculated that collagen VII may not be produced by the overlying epidermal cells or that it may be degraded before it migrates into the dermis and is incorporated into the fibrils.

A finding by NIAMS-funded researchers Drs. Lynne T. Smith and Virginia P. Sybert at the University of Washington in Seattle reveals a new way in which this crucial protein may fail to be incorporated into the anchoring fibrils. In looking at tissue samples from an EB-affected infant who died at birth, they found that type VII collagen was made in epidermal cells but remained inside these cells, rather than being released into the dermis. This failure to release type VII collagen was not seen in the unaffected parents.

Mosaicism Found Important in Hereditary Osteogenesis Imperfecta

A gene can mutate, or change, at any point in the life of the cell that contains it. A mutation sometimes occurs in a gene very early in embryonic development, when a small number of precursor cells are rapidly dividing and giving rise to different tissues. If a gene mutates in a precursor cell, the cells that divide from the precursor will contain copies of the bad gene. Cells that come from unaffected precursors will contain copies of

the normal gene. The result is a person who has a "mosaic distribution" of defective and normal forms of the same gene in his or her tissues, although clinically such a person may appear normal.

Mosaicism may be a major reason for the occurrence of lethal osteogenesis imperfecta (OI) in families in which parents are unaffected by the disease. Osteogenesis imperfecta is a disease in which improperly formed bone collagen causes bones to become brittle and break easily. Dr. Peter H. Byers and his colleagues at the University of Washington in Seattle studied a man who is clinically normal but apparently carries a gene for lethal OI: his two sons (born to different wives) were fatally affected with OI. The scientists found that some of the man's sperm carry a gene that directs the production of abnormal bone collagen and results in lethal OI. Yet his fibroblasts--body cells that produce other connective tissues--have only the normal gene, which directs the production of normal collagen. The presence of some cells that contain bad and good forms of the same gene or others that contain only the normal ("good") gene explains why he lives yet has had children who died from the disease. This research shows that both the presence of a bad form of the gene and its distribution in certain tissues is important in determining the inheritance and clinical expression of lethal osteogenesis imperfecta. The NIAMS and the National Institute of General Medical Sciences supported this work.

National Center for Research Resources

Shared research facilities provided by the National Center for Research Resources (NCRR) support a variety of studies focused on infant mortality. Recently, grantees of the General Clinical Research Centers (GCRC) Program identified a specific cause and treatment for several types of muscle weakness that can lead to coma and death. Other GCRC grantees documented the factors that cause severe lung disease in some children. The specially trained staff and sophisticated equipment of GCRCs are crucial to such clinical studies.

Research Identifies Causes of Infant Metabolic Diseases

Grantees at the Children's Hospital of Philadelphia GCRC in Pennsylvania have found methods of treating five previously unknown genetic defects that can cause infants to develop life-threatening forms of hypoglycemia (low blood sugar) and coma. According to the grantees, these disorders, which involve defects in the metabolism of fatty acids, often are confused with Reye's syndrome and sudden infant death syndrome.

According to grantee Dr. Charles A. Stanley, the defects cause deficiencies of enzymes needed to process fat into energy. All five of the disorders being studied by the researchers result in abnormally low levels of carnitine, an amino acid found in skeletal muscle and the liver. The reduction of carnitine in one of the disorders, however, is so severe that supplements of the naturally occurring chemical are needed for proper metabolism. The other four disorders can be controlled with dietary methods, Dr. Stanley says. Specifically, the patient should eat before going to sleep and again early in the morning to keep the body from unsuccessfully trying to draw upon fat stores for energy.

Factors Linked to Severe Lung Disease in Children

GCRC grantee Dr. Susan Scott at the University of New Mexico in Albuquerque and her colleagues have identified a possible cause and treatment for bronchopulmonary dysplasia (BPD), a severe lung disease that afflicts newborns.

Dr. Scott and her team found that some newborns with BPD have extremely low levels of a substance called epidermal growth factor (EGF), which has been shown to be involved in wound healing. According to Dr. Scott, BPD results partially from damage inflicted by the use of ventilators, apparatuses which help infants breathe. The injury that results from the use of the ventilators does not heal properly, apparently because sufficient EGF is not present, according to Dr. Scott. The resultant scarring puts additional stress on the infants, sometimes putting such a strain on their already weakened condition that they die.

Preliminary studies by the GCRC grantees indicate that the oral administration of certain steroids called glucocorticoids, which are sometimes given to these infants to reduce the inflammation in their lungs, stimulates the production of EGF. The investigators noticed that infants whose levels of EGF remained high after a regimen of treatment showed continued improvement. Those whose EGF levels dropped did not do well. A formal clinical trial of the glucocorticoids is now underway.

National Center for Nursing Research

Research by the National Center for Nursing Research (NCNR) to reduce infant mortality focuses on better nursing techniques to help maintain or improve health during pregnancy; to prevent preterm birth and low birth weight; to provide optimum care for preterm and low-birth-weight infants; and to promote infant health.

Safer Techniques to Help Sick Premature Infants Breathe

Premature infants with respiratory distress syndrome (RDS) require endotracheal suctioning (ETS) to remove secretions and debris from their endotracheal (breathing) tube. Although this is a necessary nursing procedure to enable the baby to breathe, it often produces dangerous complications. Research has not determined the safest and most successful techniques for the procedure.

ETS often is performed with the infant's head rotated and several suctionings are made in an attempt to improve removal of secretions. NCNR grantee Dr. Barbara S. Turner and her colleagues at Madigna Army Medical Center in Tacoma, Washington, examined the effect of head rotation and number of suctioning passes during ETS on blood oxygen levels, heart rate, pressure inside the skull, and removal of secretions in 30 newborn infants who required ETS. The study shows that ETS using head rotation results in decreased blood oxygen levels and increased pressure in the skull, and did not improve removal of secretions. Making more suction passes also did not improve secretion removal and caused decreased blood oxygen levels and increased pressure inside the skull.

This study provides extremely important new information about suctioning procedures that can help avoid dangerous complications for preterm infants with RDS.

Outlook

) While the United States ranks poorly in international comparisons of infant mortality, this country has made considerable progress in recent years in reducing its infant mortality rate. In 1988, for example, the U.S. infant mortality rate was 9.9, which marked a significant drop from the rate of 21.8 recorded 20 years earlier.

This reduction is directly attributable to increased research efforts focusing on understanding the causes of infant mortality. From technological advances in medicine to improved patient care, this research has yielded tremendous results.

In a continuing effort to improve the health of our Nation, NICHD--as well as other components at NIH--is committed to reducing infant mortality through research and intervention.

OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH

INFANT MORTALITY

The Office of Adolescent Pregnancy in the Office of Population Affairs administers the Adolescent Family Life (AFL) Program under the provisions of Title XX of the Public Health Service Act. This program helps to reduce unwanted pregnancies in a client population which is, by reason of age or socio-economic situation, particularly susceptible to poor pregnancy outcomes including neonatal death. The AFL program contributes to reductions in infant mortality not only by improving birth intervals and by reducing unwanted pregnancies, but also by directly improving maternal health through the diagnosis and treatment of sexually transmitted diseases and by the direct provision of pre-natal services in the "care" component of the program. Moreover, the program promotes parenting skills which can help to reduce serious infant morbidity and mortality by reducing the incidence of child abuse and neglect.

The range of services delivered by AFL projects include pregnancy testing, maternity and adoption counseling, referral for STD treatment, referral to pediatric care, family life education, vocational services, transportation services, pre-natal and post-natal care, adoption counseling and referral, nutrition counseling, referral to family planning services and referral to other physical or mental health services.

The AFL program provided social and health care services to 9,200 pregnant or parenting adolescents in 1989. These care projects have been successful in reducing low-birthweight, low gestational age and medical complications related with adolescent pregnancy. An additional 38,000 adolescents and pre-adolescents participated in AFL prevention projects. These prevention projects have brought about improvement in adolescents' knowledge and attitudes about delaying sexual activity. Some projects have also reported success in delaying the onset of sexual activity among teens in their programs as well as in reducing pregnancy rates.

The Office of Minority Health (OMH) is another OASH program concerned with high rates of infant mortality. One of the components of the Office of Minority Health is the Minority Community Health Coalition Demonstration Grant Program through which funding is provided for innovative community-based risk reduction demonstration grants. It is anticipated that OMH will award one coalition grant that may conduct intervention activities to combat infant mortality in a selected minority community. These intervention efforts may serve as a model which could be replicated in other minority communities.

HEALTH CARE FINANCING ADMINISTRATION

INFANT MORTALITY

Within the Department of Health and Human Services, Medicaid accounts for almost 75 percent of the expenditures for programs directed toward addressing infant mortality. To help reduce the shocking infant mortality and morbidity rates, HCFA launched its Medicaid Maternal and Infant Health Initiative in FY 1990. HCFA actively encourages States to take full advantage of every Medicaid option available for improved services to infants and pregnant women, in order to:

- o bring more eligible pregnant women into risk-appropriate health care at an earlier stage,
- o bring more infants into health supervision, and
- o improve coordination of services among Medicaid, Maternal and Child Health, and WIC programs.

HCFA helps States implement the initiative through a three-part strategy: enrolling eligible pregnant women, improving obstetric and pediatric provider recruitment and retention, and exploring service delivery options and alternatives. Through proactive outreach and streamlined eligibility processes, enrollment is achieved by seeking out eligibles and marketing preventive health programs. HCFA will match a State Medicaid agency's investment in community educational campaigns on the need for prenatal care, in targeted outreach to specific groups as adolescents or substance abusers, peer outreach workers, hotlines, user friendly intake systems and outstationed eligibility workers.

Special effort is needed to improve provider participation. At the very time when Medicaid eligibility and coverage for low income children and pregnant women is expanded, national obstetric and pediatric resources are declining. HCFA encourages States to address the wide range of providers' concerns: raising reimbursement levels and adding payment incentives for risk assessments or enhanced prenatal care, simplifying claims payment and helping with billing problems, strengthening provider relations activities, helping participating physicians deal with liability exposures and insurance, and helping providers deal with patient eligibility and related problems.

ESTIMATED OBLIGATIONS

	<u>1989</u>	<u>1990</u>	<u>1991</u>	<u>1992</u>	<u>1993</u>
	(Billions)				
HCFA:	\$2.8	\$3.1	\$3.5	\$3.8	\$4.2

MINORITY HEALTH AND ASSISTANCE

	1988 Actual	1989 Actual	1990 Actual	1991 Estimate	1992 Estimate
Public Health Service:					
Agency for Health Care Policy and Research					
Direct.....	\$2,663,000	\$951,000	\$3,997,975	\$5,913,000	\$7,963,000
Indirect.....	0	0	0	0	0
Total AHCPR.....	2,663,000	951,000	3,997,975	5,913,000	7,963,000
Alcohol, Drug Abuse and Mental Health Administration					
Direct.....	4,067,000	5,941,000	10,487,000	12,121,000	11,546,000
Indirect.....	164,076,000	252,046,000	326,369,000	403,510,000	457,307,000
Total ADAMHA.....	168,143,000	257,987,000	336,856,000	415,631,000	468,853,000
Centers for Disease Control					
Direct.....	22,500,000	34,727,924	50,148,262	52,526,262	52,526,262
Indirect.....	361,116,943	507,293,860	588,306,106	688,416,100	744,757,100
Total CDC.....	383,616,943	542,021,784	638,454,368	740,942,362	797,283,362
Health Resources and Services Administration					
Direct.....	44,851,947	46,222,078	57,591,000	129,872,000	144,850,000
Indirect.....	998,079	1,167,911	1,575,903	1,600,000	0
Total HRSA.....	45,850,026	47,389,989	59,166,903	131,472,000	144,850,000
National Institutes of Health					
Direct.....	108,269,000	147,021,000	157,172,000	215,228,000	247,763,000
Indirect.....	166,518,000	192,376,000	268,536,000	264,514,000	288,385,000
Total NIH.....	274,787,000	339,397,000	425,708,000	479,742,000	536,148,000
Office of the Assistant Secretary for Health					
Direct.....	2,793,000	2,949,000	7,956,000	18,919,000	20,000,000
Indirect.....	0	0	0	0	0
Total OASH.....	2,793,000	2,949,000	7,956,000	18,919,000	20,000,000
Total Public Health Service					
Direct.....	185,143,947	237,812,002	287,352,237	434,579,262	484,648,262
Indirect.....	692,709,022	952,883,771	1,184,787,009	1,358,040,100	1,490,449,100
Total PHS.....	\$877,852,969	\$1,190,695,773	\$1,472,139,246	\$1,792,619,362	\$1,975,097,362

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

MINORITY HEALTH AND ASSISTANCE TO
MINORITY HEALTH STUDENTS AND SCHOOLS

The purpose of the Agency for Health Care Policy and Research (AHCPR) is to enhance the quality, appropriateness, and effectiveness of health care services and to improve access to that care. This is accomplished through the establishment of a broad base of scientific research and through the promotion of improvements in clinical practice and in the organization, financing, and delivery of health care services. The AHCPR also is responsible for facilitating the development, review, and updating of clinically relevant guidelines for specific conditions and treatments. As the focal point of Federal efforts in medical effectiveness and health services research, the AHCPR seeks to create and disseminate new knowledge and better understanding of the processes by which health services are made available and how they may be provided more efficiently and effectively. The AHCPR addresses the full array of health care issues, among them minority health care.

Informed policy measures require a systematic analysis of the complex interactions of forces that affect the level and quality of access, utilization, and continuity of health care services for the disadvantaged. Alternative and practical solutions to deal with the specific health care problems of the disadvantaged necessitate an active concern for assessing their relative cost-effectiveness, efficacy, and equity.

For purposes of health services research, the definition of disadvantaged may be considered in terms of income, existing health status and the usual socio-economic covariates that imply a relatively lower class existence in the United States. The likelihood of being faced with inequities in access to health services is magnified if the individual involved is not only poor but also elderly and female, living in a rural or inner-city community, and either Black, Native American, Asian-American, or Spanish-surnamed. However, the definition of the disadvantaged can be broadened as not simply a function of income alone, but as depending on the number and kinds of access barriers that are faced, the number of special health problems possessed, and the particular personal, social, and economic characteristics of the individuals involved.

Future health services research in this area must be more policy oriented and provide information and appropriate instruments for policy decision-making and program evaluation. Attention will be directed toward analyzing systematically the interaction of the socio-economic, demographic, environmental, and institutional influences that affect health care delivery to the disadvantaged, and identifying the related policy implications and options for various levels of government. Research efforts in this area will address:

- o Barriers to access, utilization, and continuity and their modification;
- o Determinants of differential morbidity and mortality;
- o Institutional and programmatic influences on delivery and use of health services; and
- o Cost-benefit and cost-effectiveness analysis of Federal, State, and local programs.

Technical Assistance to Historically Black Colleges and Universities (HBCUs)

Traditionally, the Agency for Health Care Policy and Research (AHCPR) training awards are made to institutions that have medical or public health schools or multidisciplinary centers for health care policy formulation. We are working to increase the research capacity of HBCUs, and have targeted activities primarily to the three HBCUs with medical schools as well as to Drew Postgraduate Medical University.

In FY 1990, AHCPR initiated a number of activities relevant to HBCUs. They included: a research agenda-setting conference at Meharry Medical College, that was funded through an interagency agreement with the CDC; a supplemental award program to increase the involvement of minority health professionals in health services research and the hiring and training of minority and postgraduate fellows; the National Research Service Awards (institutional grants) supplement to recruit and train minority fellows; and the establishment of an intergovernmental personnel loan to Morehouse University.

- o The Meharry Conference on "Children at Risk" was funded with some of FY 1990 funds although it actually occurred in early FY 1991.
- o The supplemental awards were established to support minority researchers and promote investigation into minority research concerns. All grantees with two or more years of support remaining, were notified by letter and encouraged to apply for the administrative awards in order to increase the training of minority researchers and others interested in furthering minority health services research.
- o The National Research Services Awards (institutional grants) recipients were notified by letter of the Public Health Service policy and encouraged to apply for additional funding under the program for recruitment and training of minority students.

- o The AHCPR formalized an intergovernmental personnel agreement (IPA) to Morehouse University for the purpose of enhancing their health service research capacity. We expect that the technical assistance rendered by the senior level detailee will be useful in Morehouse achieving an improved research portfolio.

Medical Treatment Effectiveness/Outcomes Research

The goal of the AHCPR's Medical Treatment Effectiveness Program (MEDTEP) is improved effectiveness and appropriateness of clinical practice. The Agency helps to generate scientific and policy-relevant information on the effectiveness of alternative strategies for the prevention, diagnosis, treatment, and management of a wide variety of acute and chronic conditions. In FY 1990, several projects were supported through MEDTEP relating to minority health care. These include:

"Community Health Care Models for Diabetes Prevention and Control"

Ty Hartwell, Principal Investigator
 Research Triangle Institute
 Intraagency Agreement #AHCPR 90-16 with the Centers for Disease Control (CDC)

Using data obtained from diabetes patients, primary care providers, and hospitals, this project will: evaluate the community-level burden of diabetes mellitus and the quality and effectiveness of health care services for persons with diabetes; develop community-level models for incorporating current practice guidelines into medical and self-care; and develop and demonstrate community health promotion strategies. The project seeks to establish whether health care and promotion activities that are thought to be efficacious are effective in preventing morbidity and mortality, especially in communities with large minority populations.

Two communities will be selected to serve as intervention and control sites. One community will develop and implement a health care model for patients with established diabetes. Changes in the incidence of diabetes-related morbidity after institution of the model will be contrasted with the second community. The second community will be the site for an obesity prevention and control program intended to reduce the prevalence of obesity and incidence of diabetes. For this intervention, the first community will serve as the control.

An estimated twelve million Americans have diabetes, with over 650,000 new cases identified each year. Diabetes and its complications are more prevalent among Blacks, Hispanics, and Native Americans. In 1987, patients with diabetes spent approximately 27 million days in the hospital with total health care costs of about \$20.4 billion. Recent strides in

understanding diabetes and how to prevent or delay its complications have not been fully applied, leaving a significant disparity between the actual and attainable patterns of morbidity, mortality, and cost.

"Gastroenteritis Patient Outcome Research"

Christy Moynihan, Ph.D., SysteMetrics,
Contract No. 282-90-0043

The contractor will evaluate the available literature and data on pediatric gastroenteritis and collect and analyze data to evaluate variations in treatment, outcomes, and resource use. The study population will include American Indian and Alaskan Native populations. Clinical recommendations will be developed based on findings.

**Development/Updating of Clinical Guidelines,
Quality Standards, Performance Measures,
Medical Review Criteria**

The AHCPR promotes the quality, appropriateness, and effectiveness of health care by facilitating the development, review, and updating of clinically relevant guidelines for specific conditions. Health care providers, educators and consumers will use these guidelines to help determine how to prevent, diagnose, treat and manage health conditions most effectively. The Agency also assists in the creation and periodic updating of quality standards, performance measures and medical review criteria that may be used to assess and help ensure the quality of health care. Under P.L. 101-239, two mechanisms may be used to accomplish these: (1) panels of qualified experts and health care consumers can be convened, and (2) contracts can be issued to public and non-profit private organizations. AHCPR elected to utilize the panel process for developing the initial seven guidelines in FY 1990 and 1991.

The priorities of clinical conditions to be studied are identified in conjunction with the Institute of Medicine, the Health Care Financing Administration and professional organizations. Criteria for the selection of conditions include:

- specific needs of the Medicare and Medicaid populations;
- expected potential for reducing inappropriate variations in the prevention, diagnosis, management or outcome of a particular condition;
- number of individuals affected by the clinical condition;
- cost of the condition to all payers including patients; and

- adequacy of scientific evidence to develop guidelines and standards, etc.

All of the initial seven clinical guidelines being developed affect large numbers of minority populations: benign prostatic hyperplasia, cataracts, urinary incontinence and the prevention and management of pressure sores, pain management and depression among outpatients in primary care settings. The guideline being developed regarding sickle cell disease is of particular importance to Americans of African, Mediterranean, Indian and Middle Eastern heritage. These guidelines will be completed in FY 1991 or early FY 1992. These guidelines when completed will lead to the formulation in FY 1991 and later the creation of standards of quality, performance measures and medical review criteria.

General Health Services Extramural Research

The Agency's general health services extramural research program has a multi-faceted approach to minority health care concerns. The centerpiece of this program is the support of research, through peer-reviewed grants and contracts. In addition, the extramural research program provides technical assistance and policy analysis, facilitates timely dissemination of research findings, and works collaboratively with all concerned to assure that activities are coordinated.

Projects Ongoing in Fiscal Year 1990:

"Use of Perinatal/Infant Services by Hispanics in AHCCCS"
(Arizona Health Care Cost Containment System),
Patricia D. Moore, Dr.P.H., R.N., Arizona State University,
Grant No. HS 06127

This study is centered on utilization of pre-natal care and infant care the first year of life. The acculturation, health beliefs and utilization of two preventive services (prenatal care and infant immunization and well baby care) are being studied in 310 Mexican-Hispanic families and compared to the health beliefs and utilization patterns of 310 non-Hispanic whites who are also in a state Medicaid program, the AHCCCS program. The findings from this study will provide information on the relationship between acculturate health beliefs and preventive health practices for prenatal and well baby care.

"Alternative Health Care Utilization in the Rural Elderly"
James P. Mitchell, Ph.D., East Carolina University, Grant
No. HS 05381

Dr. Mitchell will describe and model the use of alternative health care resources by rural poor and black elderly. The variables which influence alternative care use will be identified. Seven hundred and ninety-eight rural poor and black

will be identified in 10 of the 33 officially designated rural counties in North Carolina. All respondents identified in a personal interview as users of alternative care will again be interviewed in the home. The study will identify the reasons for alternative care by rural poor and black elderly and provide clues as to the dynamics of their health care utilization.

"Mediators of Birth Outcomes Among Three Low-Income Ethnic Groups"

Ruth E. Zambrana, University of California at Los Angeles,
Grant No. HS 05518

Dr. Zambrana is examining the ethnic differences in birth outcomes among primiparous, low-income Black, Mexican-American and Mexican immigrant women who receive their prenatal care from providers in community health centers and primary care centers in public/private hospitals in Los Angeles, California. The study is designed to determine if observed differences in medical risks contribute to differences in birth outcomes, if prenatal care influences neonatal outcomes when medical risk is controlled, if stress and anxiety contribute to birth outcomes, and if the three groups differ in the social support they receive during pregnancy.

New Starts in Fiscal Year 1990:

"Use of Health & Social Services by Older U.S. Hispanics," Ana I. Alfaro-Correa, Johns Hopkins University, (Dissertation)
Grant No. HS 06603

This research will evaluate the relationship between sociodemographic and health characteristics and use of health services among elderly Hispanics. Secondary analyses will be performed on data collected from a national telephone survey of noninstitutionalized elderly Hispanics conducted in 1988. The outcome measures will include: use of health services only; use of social services only; use of both health and social services; and use of neither type of service. Comparisons among and between the four subgroups represented in the sample will be performed. This research is expected to help explicate the utilization patterns of the elderly Hispanic population and could be useful for policy analysis in the area of organization and delivery of health services for the minority aged in the U.S.

"Multilevel Practice Model for Rural Hispanics,"

Sandra L. Ferketich, Ph.D., University of Arizona, Grant No.
HS 06891

This research proposes to evaluate the success of a three-tiered community-based nursing delivery model, the Comprehensive Multi-level Nursing Practice Model, among Hispanics in a rural community setting. This model will be operationalized in the Mexican American community in rural Pinal County, Arizona. The demonstration component will develop and implement three nursing

interventions: personal preventive nursing, organized indigenous caregiving, and community empowerment. The focus of both the model and the interventions is on improving the health of the population by directing the interventions to individuals and families, groups, and the community.

"Racial Differences in APGAR Scores and Infant Mortality,"

Mary P. deHart, Johns Hopkins University, Grant No. HS 06609

The objective of this research is to assess possible racial differences in the association between one minute and five-minute APGAR scores and the mortality and early morbidity in low birthweight infants. The findings may assist in the predictive use of the one and five-minute APGAR score for treatment protocols and outcome, and explore the influence of race on both treatment and outcome.

"Nursing Effectiveness in Preventive Child Health Program,"

Dorothy S. Oda, D.N.Sc., University of California - San Francisco, Grant No. HS 06510

This project deals with pediatric health care utilization among low-income parents who are eligible for health assessments and other benefits under the federally sponsored and state operated Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program. This study will provide empirical evidence in terms of the impact of two modalities for public health nursing (PHN) services on increasing the numbers of children who have access to EPSDT. The goal is to determine if direct contact between a public health nurse and these low-income parents will produce a higher number of health assessments (medical and dental) for their children ages birth to 7 years.

General Health Services Intramural Research

A major component of the Agency's general health services intramural research program is the National Medical Expenditure Survey (NMES). Results of this survey will provide the Federal Government with current information on how much Americans use, pay for, and finance medical care.

The 1987 NMES was designed to meet the nation's need for analyzing health expenditures and public and private insurance programs. By extending data collection to the institutionalized population and by oversampling population groups of particular interest of Federal policymakers, NMES data can be used to examine a far broader range of issues than any preceding survey. Estimates based on NMES data can be employed to assess the general impact and specific effects of current programs and the potential impact of proposed legislation on the cost and use of health services across all sectors of the health care delivery system.

The 1987 NMES gathered data from a national probability sample of the civilian noninstitutionalized population. The NMES sample of approximately 14,000 civilian households (37,000 persons) includes oversampling of groups of particular policy interest: Blacks, Hispanics, the poor and nearly poor, the elderly, and persons with functional limitations. It also includes a sample of American Indian and Alaskan Native households.

The NMES Household Survey was a year-long panel collecting measures of health status, use of health care services, expenditures and sources of payment, insurance coverage, employment, income and assets, and demographic information. Household data will be supplemented by surveys of medical health insurance providers, employers, and insurers associated with the sampled persons, and by data from Medicare administrative files.

The following papers/presentations on minority health concerns were developed by staff of the Center for General Health Services Intramural Research in 1990:

Authors: Beauregard, Karen., Cunningham, Peter., and Cornelius, Llewellyn.

Title: Access to Health Care Among Native Americans

Source: National Medical Expenditure Survey Research Findings

Author: Cornelius, Llewellyn

Title: A 1987 Profile of Barriers of Access to Medical Care for White, Black and Hispanic American Children.

Source: Annual Meeting of the American Public Health Association.

Author: Cornelius, Llewellyn

Title: Health Habits of School Aged Children

Source: Annual Meeting of the American Public Health Association, 1990

Authors: Cornelius, Llewellyn, et al.

Title: Usual Sources of Medical Care and Their Characteristics, 1987

Source: National Medical Expenditure Survey Research Findings

Author: Cornelius, Llewellyn and Zulema Suarez

Title: Equity of Access to Ambulatory Care for Ethnic Minorities in the U.S., 1987

Source: Annual Meeting of the Association for Public Policy Analysis and Management.

- Authors: Cunningham, Peter., and Mueller, Curtis.
Title: **Characteristics of Residents in Facilities for the Mentally Retarded**
Source: National Medical Expenditure Survey Research Findings Number 6.
- Authors: Johnson, Ayah, and Taylor, Amy.
Title: **Chronic Diseases: A Comparison Between American Indians and Alaska Natives and the U.S. Population, 1987**
Source: National Medical Expenditure Survey Research Data Summary Number 6.
- Authors: Lefkowitz, Doris and Short, Pamela F.
Title: **The Effect of Medicaid Eligibility on Preventive Services for Low Income Children**
Source: Annual Meeting of the American Public Health Association.
- Authors: Lemrow, Nancy, Adams, David, Coffey, Rosanna, and Farley, Dean
Title: **The 50 Most Frequent Diagnosis-Related Groups (DRGs), Diagnoses, and Procedures: Statistics by Hospital Size and Location**
Source: Hospital Cost and Utilization Project
- Authors: Schur, Claudia and Cunningham, Peter
Title: **Health Care Coverage of Native Americans: Finding from the 1987 Survey of American Indians and Alaska Natives**
Source: National Medical Expenditure Survey Research Findings.
- Authors: Short, Pamela F., Cornelius, Llewellyn, Goldstone, Donald.
Title: **Health Insurance of Minorities in the United States**
Source: Journal of Health Care for the Poor and Underserved, 1, 1 (Summer 1990):9-24, 1990.
- Authors: Short, Pamela, Monheit, Alan and Beauregard, Karen.
Title: **A Profile of Uninsured Americans**
Source: National Medical Expenditure Survey Research Findings, Number 1.
- Authors: Short, Pamela F.
Title: **Estimates of the Uninsured Population, Calendar Year, 1987.**

Authors: Underwood, Carol and Lefkowitz, Doris
Title: **Personal Health Practices Among Native Americans**
Source: Annual Meeting of the American Public Health Association.

ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION

Minority Health and Assistance

National Institute of Mental Health

In recent decades it has become clear that the image of the U.S. as a "melting pot" of racial and ethnic groups is no longer an appropriate one. We have begun to accept and affirm diversity as a basis for national strength. The predominant minority populations of the U.S. can be categorized as Blacks, Hispanics, Asian and Pacific Islander Americans, and American Indians/Alaska Natives. Within each racial or ethnic category, significant subgroup differences exist, tempering generalizations about health and mental health needs and emphasizing the complexity of the task of understanding and meeting the needs of minority populations.

The perception and definition of mental illness; its identification and treatment; the spectrum of support mechanisms and their availability, appropriateness and accessibility; and help-seeking behaviors and the interaction with service providers are some of the factors that affect the outcome of mental illness. Minority population responses to these factors provide a spectrum of issues worthy of investigation. For support of minority mental health research, NIMH uses a broad range of funding mechanisms: small grants, regular research grants, FIRST Awards, program project grants, cooperative agreements, and clinical research centers. Research grants are awarded to institutions on behalf of principal investigators who design and direct a specific project. Support is available to investigators to study clinical, applied, and basic science issues relevant to minority groups.

AccomplishmentsIncreasing Research At Predominately Minority Institutions

The Minority Institutions Research Development Program (MIRDP) was established in FY 1990 to increase the capacity of minority institutions and their faculty to conduct rigorous ADM research. The five MIRDP grants awarded by NIMH in FY 1990 will assist institutions in augmenting and strengthening their research infrastructure. The grants will also support research development activities for faculty interested in conducting ADM research. Minority students will benefit from participation as research assistants. This new program complements the strong efforts NIMH has made in promoting research careers for minority students.

Efforts to Increase Minority Participation in AIDS Research

To increase the participation of minority scientists in research on HIV infection and AIDS, the NIMH Office of AIDS Programs initiated a Technical Assistance Program for minority researchers. Phase I was comprised of a workshop that provided basic orientation to the grants application process and the theoretical and applied aspects of research on AIDS. Phase II will provide intensive individual research consultation leading to eventual submission of research applications particularly focusing on the special and unique concerns of minority populations.

Minority Mental Health Research Centers

Minority Mental Health Research Centers were developed to conduct research and research development programs relevant to minority groups. The centers also provide a setting for the training of minority students as researchers. These centers are problem-oriented, comprehensive and multi-disciplinary in their approach. Each center has a clearly defined set of scientific problems of major importance to the understanding of a specific minority group. The centers provide a research environment wherein hypothesis development and testing can unfold in the context of both pilot and follow-up studies, and where new methodologies and data gathering techniques can be developed and tested.

In a major new impetus for minority population research, NIMH funded two new Minority Mental Health Research Centers in FY 1990: the Research Center for Black Mental Health at the University of Michigan and the Research Center on the Psychobiology of Ethnicity at the University of California at Los Angeles. The latter has been established to examine ethnic differences in response to psychoactive medications. These two centers brings the number of minority mental health research centers to six. The other centers are: an American Indian and Alaska Native Mental Health Research Center at the University of Colorado Health Sciences Center; the National Research Center on Asian American Mental Health at the University of California at Los Angeles; the Hispanic Research Center at Fordham University; and the Center for Cross-Cultural Research at the University of Texas Medical Branch at Galveston.

Clinical Responses To Psychoactive Medications

Clinical reports over the past several decades indicate that Asian patients generally respond to substantially lower doses of antipsychotic medications than White patients, and have more severe reactions when treated with comparable doses. Researchers at the University of California at Los Angeles have confirmed these observations. They discovered that although a dose of medication tailored for each patient resulted in similar blood levels, there were significant differences in drug activity that affected patients' clinical responses. These findings should aid in targeting psychiatric medications more appropriately to the needs of individual patients.

The Inclusion of Minorities In Research Projects

In FY 1990, ADAMHA and the National Institutes of Health (NIH) issued a joint statement concerning the inclusion of minorities in study populations. This statement was published as a reiteration and further interpretation of existing ADAMHA/NIH policies addressing this issue. Because there are clear scientific and public health reasons for specifically including members of minority groups, ADAMHA and the NIH now require that proposals for research support include minorities in study populations, unless compelling justification exists. All aspects of clinical research are subject to this policy, including human studies of the etiology, treatment, diagnosis, prevention, and epidemiology of diseases, disorders and conditions, and also including but not limited to clinical trials and research on health service and its impact on disease. ADAMHA and NIH recognize that it may not be feasible or appropriate in all research projects to include the full array of minority populations; however, applicants are urged to assess carefully the feasibility of including the broadest possible representation.

While the focus of this policy is on the inclusion of minorities in general population studies, ADAMHA and NIH also encourage attention to gaps in knowledge about specific minorities and health problems that significantly affect them. The need to address such gaps may be appropriate justification, in some cases, for focusing a particular study on a single group.

Current Activities

Prevention Intervention for Socially Rejected Black Youngsters

Socially rejected children have been found to be at greater risk for mental health problems than non-rejected children. Research being conducted at Duke University is focusing on Black pre-adolescents identified as "at risk" because of poor peer relations. A sample of rejected youngsters is being given a 6-month program of social relations training, and a subset of low-achieving youngsters also received special academic tutoring. Effectiveness of the programs will be determined by relative incidence of psychological disorder, delinquency, school dropout rate and teenage pregnancy beginning two years after the completion of intervention.

Interventions To Improve Learning And Behavior

Learning problems at an early age are important predictors of psychiatric symptoms, particularly depressive symptoms and possibly depressive disorder in adolescence. Early aggressive behavior involving breaking rules and fighting also has been found to predict later antisocial behavior, criminality and substance abuse. Interventions directed at learning and behavior management are being tested in inner-city schools by Johns Hopkins University's Preventive Intervention Research Center. The first intervention consists of a strengthened curriculum for the entire class (first and second grades), to improve reading

and other academic skills. The second intervention, also directed at the entire class, involves a behavior management method that rewards pro-social behavior. The effectiveness of these interventions will be assessed annually through the sixth grade. Characteristics of the child other than the problem behavior (e.g., neuropsychological status, perception of self competence and characteristics of family, classroom and neighborhood environment) will be used to explain differences over time in response to the two interventions.

Mental Health and Social Support in Black and Hispanic Mothers

Social support has been frequently implicated as a mediating variable between stress and psychological symptoms. As a result, interventions manipulating social support systems of high-risk individuals are a common prevention strategy. A prospective longitudinal study is assessing the extent, types, sources and changes over time of the typical support available to Black and Hispanic mothers of chronically ill and seriously, acutely ill children. Recent findings indicate that the absence of a male confidant predisposes women to depression after a stressful life event.

Minority Research Training

The objective of NIMH programs that concentrate on minority trainees is to ensure that minority investigators have a prominent leadership role, with outstanding training and a full range of research opportunities. The Minority Access to Research Careers (MARC) program provides support for honors undergraduates and faculty fellowships. Grants are made to institutions with substantial minority enrollments to provide high-level research experiences for promising college students working closely with a faculty sponsor. Support is also provided for selected faculty members to undertake more specialized research fellowships. Awards were recently made to three new MARC programs--the University of Puerto Rico at Rio Piedras, the University of New Mexico and the University of Hawaii at Manoa. A total of 12 institutions now participate in this effort.

Support for research training is also available to graduate students in key disciplines (psychiatry, psychology, neuroscience, sociology, nursing and social work) through the Minority Fellowship Program (MFP). These research training awards are made to national professional associations. MFP directors and selection committees at the respective associations, in turn, recruit, select, and closely monitor highly qualified graduate students in accredited doctoral programs throughout the country.

With other ADAMHA Institutes, NIMH is supporting an initiative to increase the number of underrepresented minority scientists participating in biomedical and behavioral research as a means of addressing the national problem of a declining scientific pool. The Supplements for Underrepresented Minorities in Biomedical and Behavioral Research program provides administrative supplements

for ongoing projects to attract and encourage minority individuals who wish to pursue biomedical and behavioral research careers. By providing these opportunities at specific points in the research career development of minority scientists, ADAMHA will substantially increase the number of minority investigators in biomedical and behavioral research. In FY 1990, NIMH funded 38 supplemental awards for minority undergraduate students, minority graduate research assistants and minority investigators.

The Future

NIMH is committed to coordinated and focussed research on the mental health needs and problems of minority populations. Such research can help to determine whether and how mental disorders disproportionately affect minority populations and how best to prevent and treat them. We also must ensure that there is a nationwide cadre of trained scientists able to contribute to our expanding knowledge of mental disorders. At stake is the quality of science in the U.S. and our need to nurture and cultivate our diverse human resources for the future.

National Institute on Drug Abuse

NIDA has a broad program relating to the needs of special populations including research, outreach, and education/training efforts. General areas over the past year have included studies in epidemiology, prevention demonstrations, research dissemination, and technology transfer; highlights include epidemiologic surveys, women, and AIDS prevention and education efforts.

Epidemiology

Minority groups are at greater risk of encountering illicit drug use. The latest available data on drug use in the general population, from the 1990 National Household Survey on Drug Abuse (NHSDA), indicate that the prevalence of drug use within the household population is generally higher in central cities than in suburban or rural areas. Minority populations by and large reside in urban areas; while Blacks account for approximately 12 percent of the total U.S. population, 57 percent live in high drug use areas, central cities. The situation for Hispanics living in families is similar; Hispanics comprise about seven percent of the U.S. population with 55 percent living in central cities. Conversely, although Whites account for 85 percent of the U.S. population, only 27 percent reside in central cities thus reducing their chance of exposure.

Past month use of any illicit drug was 6.6 percent in 1990 among Hispanics. The rate for non-Hispanic Whites is 6.2 percent for 1990. Past month drug use of non-Hispanic Blacks was 8.6 percent in 1990, down from 15.7 percent in 1985. The trends for past year cocaine use are not as encouraging for minority groups, however. The rates of past year cocaine use for Blacks and Hispanics did not significantly change from 1988 to 1990, while the rates of past year cocaine use for Whites declined significantly from 4 percent to 2.8 percent. Similarly, current cocaine use decreased dramatically for Whites, from 1.3 percent in 1988 to 0.6 percent in 1990. Rates of current cocaine use however, for Blacks, were 1.7 percent, and 1.9 percent for Hispanics. As reported by the Drug Abuse Warning Network (DAWN), among all racial groups, Blacks have the highest rates per 100,000 U.S. population of emergency room episodes for cocaine, heroin, and marijuana.

Racial, ethnic, and cultural factors have an influence on virtually every area of drug abuse. The 1989 High School Senior Survey indicates that rates of use of marijuana, inhalants, cocaine, alcohol and cigarettes are lower among Black seniors when compared with Whites. Cocaine use among White seniors is more than three times the rate for Blacks for lifetime prevalence and annual use. Because the high school survey assesses prevalence based on data collected on a particular day, it must be remembered that absentees and dropouts will not have been questioned. Since the dropout rate for minorities is higher than for Whites, and since drug use is higher among dropouts than for

those in school, it is likely that the prevalence of drug use among minorities in this age group is underestimated.

This year NIDA has modified this survey to include eighth and tenth graders. An interesting question is what happens to the minority high school students who do not use drugs to the same extent as their non-minority peers. Continuing follow-up panel studies of a subsample of those students attending at least a two year college is being conducted to assess this question. Information from these studies will carry implications for the development of prevention strategies to reach this population. Studies of dropouts are also planned.

Adverse consequences suffered by minority populations include not only negative effects on employment, school achievement, and family stability but also increased morbidity and mortality. AIDS is one of the most tragic of these consequences. As of July 1990, Black and Hispanic adults comprised 43 percent of reported AIDS cases, of which 20 percent were related to injection drug use. Seventy-seven percent of pediatric AIDS cases are Black or Hispanic, of which 50 percent were from mothers associated with injection drug abuse as a risk factor for AIDS.

Women

Women of childbearing age engage in substance abuse to a significant degree. The NHSDA reports that in the past year, 19 percent of White, 15 percent of Black, and 16 percent of Hispanic women age 15-44 used some illicit drug. Past year cocaine use was reported by 5 percent of White, 4 percent of Black, and 6 percent of Hispanic women, while past year marijuana use was reported by 13, 12, and 11 percent respectively. Alcohol use carries negative health consequences for infants exposed in utero, and was reported by 79 percent of White, and 59 percent of Black and Hispanic women. The data clearly indicate that women of all races use drugs, licit and illicit during pregnancy. A NIDA funded study conducted in Florida, substantiates these data. He found that the use of illicit drugs during pregnancy is common among pregnant women, regardless of race and socioeconomic status. Although Florida state law requires reporting any pregnant woman using drugs to health authorities, disparities in reporting practices seemed to occur along racial lines. Significantly, Black women were 10 times more frequently reported to the health authorities than White women.

NIDA sponsored investigators have conducted extensive studies among Hispanic and Black women in California that have resulted in the development of instruments to assess mediating and outcome variables that can guide HIV prevention efforts in minority cultures. This instrument measures concerns and sources of stress in minority women at risk for HIV infection. Previously, standard outcome measures have not been developed and standardized on minority women; this instrument is an important

tool for quantifying sources of stress in a minority female population.

Use of this instrument has clarified concerns and stresses of Hispanic women and has shown that the major concern of these women is to be an adequate provider for their family, especially their children. Threats to this provider role (poverty, potential loss of health, lack of information) are situational realities that must guide any intervention. In addition, minority women high in self-esteem and sense of coherence engage in fewer HIV risk behaviors. Also, women able to access social resources engaged in fewer risk behaviors. These results should guide prevention/intervention strategies to empower women to improve their lives and avoid HIV infection.

AIDS Prevention/Interventions

NIDA considers drug abuse treatment as a primary strategy for the prevention of the spread of HIV infection. The NIDA-supported National AIDS Demonstration (NADR) projects begun in 1987 have collected information on the efficacy of outreach strategies designed to interface with two populations at significantly high risk for contracting and transmitting HIV: IDUs and their sexual partners. As of July 1, 1990, the projects included 40,000 IDUs and their sex partners in 41 community-based programs. Preliminary data (as of January 1990) is based on follow-up interviews of 1,584 participants, the majority of whom are male (73 percent), Black (41 percent) or Latino (35 percent), under the age of 35 (56 percent), have at least a high school education (54 percent) and were unemployed at the time of interview (55 percent). Illegal activities, including prostitution, were a major source of income for 27 percent of the total.

The vast majority of at-risk women are members of ethnic minorities. Women, in general, have been particularly difficult to recruit into studies and therefore, comprise a minority of outreach participants. Among the injection drug users, 48 percent are Black and 18 percent Hispanic; among non-injection drug users, women who have sexual partners who inject drugs are 57 percent Black and 33 percent Hispanic. Many relied either on welfare programs (33 percent IDUs, 46 percent sexual partners) or illegal activities for their income; only 11 percent reported a spouse or sexual partner as their major source of income. In addition to 12-13 percent being homeless, many women also faced the major family responsibility of child-rearing alone. Seven percent of injection drug using women and ten percent of non-injecting women were pregnant at the time of interview.

In other investigations, a prevention/intervention program targeted towards Blacks was developed and evaluated. This is a risk-reduction program for injection drug users who were either in methadone programs (n=188) or recruited "off the streets" (n=469). Participants were primarily Black males. The intervention consisted of presenting information through a film made by minority members, together with specific AIDS counseling.

A number of risk reduction strategies, with emphasis on quitting drug use and safer sexual practices were employed. Post-intervention test scores on measures of needle and "works" sharing and bleach use indicated changes toward risk reduction behaviors. Similarly, a number of indicators of drug use also showed declines. This study is important because it addressed an area of low HIV-prevalence (3-6 percent seropositivity in IDUs), and showed that it is possible to motivate persons and change behavior in low prevalence areas.

AIDS Education/Risk Reduction

NIDA continues to offer technical assistance to minority communities across the nation. In April 1990, NIDA cosponsored a second national conference on drug abuse and AIDS prevention for the Asian American community. Three regional conferences were held for the Black community; two additional regional conferences and a national conference will be held in FY 1991. Planning also continues for three regional conferences and one national conference for Hispanic Americans.

Over the past several years, NIDA has developed a series of prevention training programs to familiarize drug abuse counselors with the needs of special populations, including high-risk adolescents, Hispanic women, and Blacks. The training includes workshops and comprehensive programs providing education and skills building. It is estimated that by the end of 1990 over 11,000 treatment counselors and service providers will have been trained in at least one comprehensive HIV prevention counseling course and up to two advanced courses.

In July 1990, NIDA and the Advertising Council launched a new mass media campaign aimed at preventing drug abuse and AIDS among teenagers. The campaign, "AIDS: Another Way Drugs Can Kill," consists of three television spots, three radio public service announcements, a 60-second movie trailer, print ads and posters. To help ensure that the ads will appeal to teens, the public service announcements for television were filmed as mini-movies by Oscar-winning director Martin Scorsese and narrated by director Spike Lee. The television spots were distributed to all network and local stations in the country. The radio public service announcements were issued to network and local stations throughout the country who cater to teens. Print ads were distributed to all U.S. daily papers and magazines that target adolescents as well as consumer magazines and outdoor advertisers.

Minority Research Training Programs

An important part of minority-related drug abuse research is the participation of appropriately trained minority drug abuse researchers. In support of the recommendations made by the Secretary's Task Force on Black and Minority Health, NIDA supports Special Population Research Training Programs that include: 1) MARC, MBRS, Supplements for Underrepresented Minorities in Biomedical and Behavioral Research Supported by ADAMHA, Minority Institution Research Development Program (MIRDP), Minority High School Apprenticeship Program, and AIDS research training; 2) grants technical assistance; and 3) research training and research grants submitted by special populations researchers and others interested in examining drug abuse among special populations. Particular emphasis is placed on recruitment of faculty from historically Black colleges and universities into these research programs.

The Special Population Research Development Program provides scientific and methodologic mentoring to ethnic minority investigators seeking to engage in drug abuse research activities. These efforts concentrate on developing statistical and analytical skills, identifying and validating research instruments and methods, and other research applications.

National Institute on Alcohol Abuse and Alcoholism

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) supports the training of minority students for careers in alcohol research and activities both to encourage the involvement of minority investigators in alcohol research and to stimulate interest in research of special concern to minority populations. The research programs of the Institute include studies in which there is a strong focus on alcohol problems among racial and ethnic minority groups and communities.

NIAAA promotes minority participation in alcoholism research through its Minority Health and Assistance Initiatives. The Institute is supporting research and training grant awards at six historically Black colleges and universities. We plan to develop and enhance the research capabilities of the by encouraging their collaboration with more established NIAAA-supported researchers.

Research grant programs designed to attract minority investigators into alcohol research include the Minority Access to Research Careers (MARC), the Minority Biomedical Research Support (MBRS), the Minority Institutions Research Development Program (MIRDP), and the Minority Alcohol Research Scholar Program. These programs are intended to attract minority honors students into research careers; strengthen biomedical and behavioral research capabilities of minority institutions; and support minority scholars who provide nationwide technical assistance to alcohol research scientists involved in minority studies. The Institute is also participating with NIMH and NIDA in a special program through which supplements are awarded for underrepresented minority scientists and students to obtain experience in biomedical and behavioral research.

Current Activities

Racial differences in the incidence of alcohol sensitivity and alcoholism may be, in part, attributed to genetic background. NIAAA is conducting research to examine the biological and genetic variation of minorities to identify the factors influencing susceptibility to alcohol abuse and alcoholism. Researchers will compare data from various epidemiological studies on familial alcoholism to evaluate specific differences among minority populations. Studies also address drinking patterns in minority populations, along with social and cultural factors affecting alcohol consumption, and associated behavioral problems. Part of NIAAA's effort on fetal alcohol syndrome has been to determine why some minority groups appear to be at high risk.

The Institute plans to intensify efforts to develop an objective measure of alcohol consumption to aid in the evaluation of the possible effect of moderate maternal drinking.

NIAAA is studying the medical consequences of alcoholism to reduce the morbidity and mortality rates associated with heavy drinking. Alcohol use is a factor in a wide range of serious and often fatal disorders including cancer, cirrhosis of the liver, and AIDS, and epidemiological studies suggest that some minorities are at a higher risk of developing these diseases. NIAAA is striving to develop new knowledge to understand the impact of alcohol use on behaviors that increase the risk of contracting AIDS in populations that have a higher vulnerability. In consultation with the National Institute on Drug Abuse (NIDA), the Institute is also evaluating treatment interventions for homeless individuals with alcohol and/or other drug problems. Minority populations have been included in this research demonstration project, since many minorities are overrepresented in the homeless population.

Hispanics

Studies of alcohol consumption among Hispanic Americans have generally concluded that there is a higher prevalence of current heavy drinking and alcohol-related problems among Hispanic males than non-Hispanic males. Hispanic females, however, have lower rates of heavy drinking and alcohol problems, and higher rates of abstinence. Studies have also pointed out that alcohol problems among Hispanic males do not decline from the twenties to thirties as occurs in the general U.S. population.

Hispanics reveal different drinking patterns that are dependent upon their country of origin. The proportion of abstainers among immigrant Mexican-American women is considerably higher than among women in Mexico, in direct contrast to increased alcohol use by immigrant Mexican men. Mexican American men have both the highest rate of abstinence and the highest rate of heavy drinking when compared with Cubans, Puerto Ricans, and other Latin Americans. Current analytic efforts include patterns of consumption as a function of immigrant status, acculturation, urbanity and region; the relationships between consumption and diagnosis, physical functioning, utilization of health services, and depression.

One study investigating the natural history of drinking and drinking-related behaviors and problems among Puerto Rican men is currently in the data collection phase; analytic work will begin next year. Research is also underway to study Puerto Rican adults to provide basic epidemiologic data on the drinking behavior and drinking norms of mainland Puerto Ricans, and to compare these findings with those on Mexican Americans. A comprehensive analysis of drinking practices and alcohol-related family problems among families of Mexican descent in an urban U.S. community is yielding a clearer picture of how the environment in which U.S. Mexicans reside may systematically alter both patterns of social relations and drinking patterns.

Blacks

Population studies have shown that while Blacks have higher proportions of abstainers relative to Whites; among drinkers, Blacks have proportions of heavier drinkers similar to other groups. Recent studies indicate that these differences emerge as a function of age. While frequent-heavy drinking appears to decline with increasing age among young adults, frequent-heavy drinking among Blacks increases. This age trend is consistent with other studies that show that Black teenagers generally have lower rates of alcohol use when compared with Whites. Although overall drinking levels are lower among Blacks, higher rates of drinking-related problems (medical, personal, and social) are reported for Black males than for White males.

An increased incidence of Fetal Alcohol Syndrome is found in Black and American Indian mothers of low socioeconomic status. The estimated rate in these populations was 2.6 per 1,000 compared with 0.6 per 1,000 when the mothers were White and of middle socioeconomic status. Although Blacks seem to be more susceptible to the deleterious effects of prenatal alcohol exposure, it is clear that no ethnic or racial groups are immune to the teratogenic actions of alcohol.

Two intramural studies have been initiated that compare sex matched, age-similar, and socioeconomically similar, Black and White alcoholics. Preliminary results indicate that there appears to be no significant differences with regard to psychopathology between Black and White alcoholics, though there are sex differences. However, the offspring of parental alcoholics do suffer from a broader range and greater degree of psychopathology, including alcoholism and major depression. For alcoholism, being male appears to be a significant risk factor; females are significantly more at risk for major depression.

American Indians and Alaska Natives

The mortality rates for American Indians and Alaska Natives reflect the extent of alcohol-related problems. Alcohol-related deaths for 25 to 44 year old American Indians and Alaska Natives are particularly prevalent. In this age group, the 1985 mortality rate for unintentional injuries was three times that of the rate for the U.S. as a whole, and the death rate for cirrhosis was 5 times that of the general population. Although American Indian and Alaska Native women drink considerably less than men, they account for nearly half of cirrhosis deaths.

As in many Indian societies, alcohol has a tragic impact for the Cheyenne, Pima, and Jemez Pueblo populations; alcoholism accounts for more than 50 percent of deaths in these communities and degrades the quality of family and social relationships. One intramural study is underway to identify alcoholism risk genes. This involves collecting and testing for linkage in families in which alcoholism is highly prevalent. Careful, structured, in

depth evaluations will permit accurate comparisons of the clinical phenomenology of alcoholism in these Indian populations with each other and to Whites. Scientists expect to gain clues as to the causes of alcoholism by defining age of onset and severity, by accurately defining psychiatric comorbidity, and by following the transmission of pathologies in families.

Other research underway with urban American Indian adolescent alcohol and drug users will provide a description of the prevalence and change over time of substance abuse in this population. It will also identify the risk and protective factors that promote or inhibit initiation and continued abuse, and will develop a screening battery for early identification of substance abusing urban American Indian adolescents.

Asian Americans

Population studies indicate that the overall prevalence of alcohol consumption and alcohol abuse is generally lower among of Asian Americans when compared to the general U.S. population. These findings are based on small samples of Asian Americans and are restricted to specific geographic areas. NIAAA has undertaken several analyses of data from a U.S.-Japan collaboration to compare the patterns of alcohol use between Japanese and Japanese-Americans. One study found a stronger association between drinking norms and drinking levels among Japanese-Americans than among Japanese. Abstainers in Japan, however, showed far more permissive attitudes toward moderate to heavy drinking than did Japanese-Americans in a number of specific drinking situations. Men and women in Japan had a more permissive attitude toward drinking when they were with small children. In contrast, for drinking before driving, the Japanese indicated much less permissive attitudes.

Prevention

Despite the diversity within the four major racial and ethnic minority groups, there are collective patterns of alcohol use and alcohol-related problems that may be quite different from those of the population as a whole. To enlarge the portfolio of minority-oriented grants, the NIAAA is currently developing a program announcement that focuses on Blacks, Hispanics, and American Indians. It summarizes what is known about the prevalence of alcohol-related problems among these particular ethnic populations; unanswered questions concerning these problems (e.g., discrepancies between self reported use or abuse of alcohol and morbidity/mortality statistics); and suggested remedies for the identified problems. Although many prevention programs are targeted toward these minority groups, very few attempts have been made to conduct prevention research. This announcement describes a number of opportunities for pre-intervention and intervention research. It also describes methodological approaches that can enhance the development of viable prevention research.

Office For Substance Abuse Prevention

Historically, the strategies, programs, and services of the Office for Substance Abuse Prevention (OSAP) have been structured to address alcohol and other drug prevention needs of multi-cultural ethnic communities. Ethnic minorities are disproportionately represented among many of the at risk populations targeted by the OSAP demonstrations programs. As a result, special efforts have been made to ensure that OSAP programs are culturally relevant.

From FY 1987 to FY 1990, OSAP has funded 245 High-Risk Youth demonstration grants and 100 Model Projects for Pregnant and Postpartum Women and Their Infants. The majority of these programs are run by minority organizations and serve minority populations. Of the High-Risk Youth grants approximately 25 percent target Black populations, 11 percent serve multiracial communities, 9 percent target Native Americans, 23 percent target Hispanics, 4 percent target Asians and Pacific Islanders, and 28 percent target Whites. Of the 100 Pregnant/Postpartum Women grants, 52 percent of the programs target multiracial populations, 20 percent target Black populations, 13 percent target Whites, 6 percent target Hispanics, and 1 percent target Asian/Pacific Islander populations.

OSAP provides technical assistance and capacity-building services to grantees and other minority organizations to ensure that these groups have the organizational and business skills to secure funds, conduct sound prevention programs, evaluate programs reliably and publish results, and accomplish other tasks necessary to advance the state of knowledge of prevention in general, and especially of prevention with minority populations. OSAP offers numerous support services to grantees, and especially attempts to ensure that programs use culturally-sensitive and specific materials. OSAP maintains a database and copies of effective culturally-sensitive materials that are disseminated to grantees upon request through contractors. Technical assistance in the form of speakers, training, financial management, general management, and other skills, is offered to all grantees.

In order to attract more minority organizations to apply for OSAP grant monies, the OSAP conducts a series of Technical Assistance Workshops throughout the country in advance of each application deadline. OSAP has made a special effort, through special mailings and invitations, to ensure that minority organizations are aware of the workshops and are invited. Technical Assistance Workshops assist prospective grantees with all aspects of the grant application process, from developing a new and innovative prevention concept, to planning for the operationalization of this concept, to filling out the details of each section of the application form.

In addition, OSAP has begun several initiatives focused on minority populations that will continue and expand. The African-

American Work Group is a group of researchers, prevention experts, and others which was convened in August, 1989 to review current prevention demonstration programs and their impact on the Black community. Dr. Lawford Goddard was commissioned to further study targeted Black grantees to determine "what works" in attracting and retaining the target population, intervention strategies, and working with families and communities. Special attention will be given to Black adolescent males aged 13-19 years, and preadolescent aged 8-12 years. The resulting report will be disseminated to alcohol and drug abuse professionals to enhance their ability to respond to Black communities. In addition, Dr. Goddard and members of the Work Group will develop several prevention/intervention response models, including an Afro-centric model and one designed specifically for high risk Black youth.

OSAP provides support for the Secretary's Black Male Initiative including OSAP staff representation to this effort. One spin-off from this involvement is OSAP's sponsorship of "The Second National Conference on Preventing and Treating Alcohol and Other Drug Abuse, HIV Infection and AIDS in Black Communities: From Advocacy conference is designed to: foster locally-based strategies to disseminate state-of-the-art information about what works in the Black community; focus talent to design, test and replicate innovative prevention and treatment services for Black males; promote understanding about the complexity of the issues regarding alcohol and other drug abuse in Black communities; and advocate mentoring programs.

OSAP has also convened an Hispanic High Risk Youth Work Group consisting of OSAP grantees and other professionals experienced in working with this target population. The purpose is to synthesize knowledge, examine theory and practice, and study issues specific to the development of prevention and treatment strategies for high risk Hispanic youth. This group has met and has commissioned a study by two well-known Hispanic experts to review the literature on prevalence among, and prevention/intervention models for this population, and to analyze OSAP grantees serving this population. The emphasis of efforts of this work group is to advance the state of knowledge of what works with this population, to bridge the gap between theory and practice, to respond to the needs of OSAP grantees serving this population, and to expand the network of Hispanic groups involved in addressing the problems of high risk Hispanic youth.

Native American initiatives have included a study which provided an overview of prevention programs targeted towards Native Americans which was disseminated to all OSAP grantees and widely throughout the field. A Fact Sheet was developed from the results of this study and is available through OSAP's National Clearinghouse on Alcohol and Drug Information, which disseminates information and materials throughout the country. In addition, OSAP requested a study of culturally-relevant evaluation tools for Native American populations. The results of this study

clarified the intense need for such materials in the prevention field.

OSAP has actively supported ADAMHA's historically Black colleges and universities initiative in compliance with President Bush's Executive Order. Three HBCUs received high-risk demonstration grants: Edwards Waters College, Jacksonville, FL; Coppin State College, Baltimore, MD; and Southern University, Baton Rouge, LA. Each is using a unique and different approach in its prevention demonstration program.

In addition to materials development and publications in support of technical assistance and other program efforts, OSAP has attempted to remedy the serious shortage of culturally relevant materials for service providers who work with multi-cultural youth and families. Through the National Clearinghouse on Alcohol and Drug Information (NCADI), culturally-specific materials are collected and distributed. NCADI maintains mailing lists of minority organizations across the country for special mailings of targeted and culturally-relevant materials. OSAP continues to develop new materials targeted for High Risk Target Groups with bilingual materials published for youngsters and adults. In addition, multi-cultural materials are distributed routinely through the Department of Agriculture's Women, Infants and Children (WIC) centers, through OSAP's National Clearinghouse for Alcohol and Drug Information, through our nationwide network of Radar Resource Centers, and through other appropriate channels.

OSAP's program efforts toward minority populations have continued in FY 1990 and have been enhanced through the addition of two new programs. The Community Partnership program, initiated during FY 1990, is a cross-cultural or multi-cultural program based on the needs of individual communities. This effort supports the formation of public/private sector partnerships in individual communities across the Nation to develop comprehensive programs for substance abuse prevention and treatment. During FY 1990, 95 awards were awarded. Of these, approximately 35 percent target Black populations, 3 percent target Native Americans, 16 percent target Hispanics, 2 percent target Asians and Pacific Islanders, and 44 percent target Whites.

Also during FY 1990, 14 awards were made to support innovative approaches designed to reach hard-to reach and/or high-risk audiences in specific populations through mass communications or that respond to demonstrated needs for specialized materials targeted to populations in high-risk environments. Of these, approximately 15 percent target Black populations, 8 percent target Native Americans, 23 percent target Hispanics, 8 percent target Asians and Pacific Islanders, and 46 percent target Whites.

OSAP support of minority health care initiatives is in keeping with ADAMHA's commitment to establish linkages, promote

communication, cooperation, and networking in support of "capacity building" for the development of effective prevention programming for multi-cultural ethnic minorities. OSAP hopes to attract more minority applications for demonstration grant funding, and will continue to offer numerous types of technical assistance.

Office for Treatment Improvement

The Office for Treatment Improvement (OTI) was created in FY 1990 to provide a focal point within ADAMHA to meet the expanding Federal effort to promote and enhance existing programs and new approaches in the treatment of drug abuse and the associated problems of alcoholism and mental illness. In recognition of the urgency of this mission, OTI identified priorities that form the cornerstone of the overall treatment improvement strategy: 1) developing enhancements of treatment services in high need and intensity areas of drug abuse; 2) developing specialized treatment enhancement programs for critical populations including racial and ethnic minority populations; and 3) criminal justice system programs with specific emphasis on incarcerated drug abusers and those on probationary release.

The OTI strategy with respect to its discretionary grant programs is to support innovative mechanisms to improve the delivery of treatment services at both the individual program level and the broader systemic level. For many racial and ethnic minority populations, who are disproportionately represented among those at-risk of substance abuse or those in treatment, OTI grants are intended to provide a mechanism to link, integrate, and improve existing treatment services with other relevant community-based health and mental health services.

OTI will continue to utilize these grant programs to improve the effectiveness and efficiency of drug abuse treatment delivered to minority populations. Through the diverse complement of community-based and culturally/ethnically focused programs funded, it is hoped that we will not only improve the delivery of treatment services by one program to one community, but achieve a broader, system-wide impact on many programs and communities.

Treatment Grants in Crisis Areas

The Treatment Grants in Crisis Areas program is designed to provide large cities that have a high incidence of drug abuse with funds to improve their system for the delivery of drug abuse treatment services. In FY 1990, OTI awarded eight treatment improvement grants to New York; Boston; Baltimore; San Juan, Puerto Rico; Atlanta; Milwaukee; Albuquerque; and Los Angeles. While this program is not intended to provide services exclusively to racial and ethnic minority populations, the nature of the epidemiology of drug abuse, especially in these cities, indicates that a substantial impact can be achieved on drug

abusers from these groups. Based on a consideration of the number of racial and ethnic drug abusers to be served in these various target city programs, we estimate that approximately 75 percent of the target city funding impact racial and ethnic minority populations.

Critical Populations Grant Program

The Critical Populations grant program supports treatment improvement initiatives among existing treatment providers to enable them to provide a more comprehensive array of services to at-risk population groups that are facing critical primary health and socioeconomic difficulties as a result of their drug abuse. The three critical populations identified as the target populations for these treatment improvement funds include: (1) minority populations; (2) adolescents; and (3) residents of public housing.

Of the total number of grants awarded in FY 1990, 45 percent identified one or more racial and ethnic minority population as the target population. Twenty-one percent of the projects funded were adolescent projects that also targeted minority adolescents. Public housing represented six percent of the total grants awarded, but virtually all of these grants targeted a minority population. Finally, 14 percent of the total awards made were to programs which targeted multiple target populations and minority populations.

Criminal Justice Grant Program

The model drug abuse treatment program for correctional settings was developed to enhance the quality of existing drug abuse treatment for incarcerated individuals, with the ultimate goal of improving treatment outcome. Projects funded had to demonstrate emphasis consistent with the prevalence of the racial and ethnic minority populations in the affected correctional setting.

The model drug abuse treatment program for non-incarcerated criminal justice populations was developed to improve treatment outcome for diversionary and high risk populations (who were also adolescents and/or racial or ethnic minorities) and reduce the frequency with which these populations interact with the criminal justice system and/or engage in criminal behavior because of their addictive disorders.

In FY 1990, OTI funded a total of 19 projects as part of these two grant programs. Of the total number of projects funded, approximately 46 percent of funds awarded impact directly on various racial and ethnic minority populations.

Waiting List Reduction Program

The Waiting List Reduction Grant Program was developed to help existing drug abuse treatment programs expand their capacity to

serve drug abusers on waiting lists to receive treatment. In FY 1989 and 1990, 72 percent of the 357 grants awarded impacted on treatment for minority populations.

Summer Fellowship in Addiction Medicine and Treatment

The Summer Fellowship in Addiction Medicine and Treatment was developed in recognition of the need to provide minority medical students with a focused, front-line view of the medical aspects of addiction. The program's objectives were to:

- o Increase the overall sensitivity of minority medical students to addiction as a disease;
- o De-mystify and correct many of the misconceptions and biases which exist in the care and treatment of those with addiction disorders; and
- o Provide a learning mechanism to relate the care and treatment of the addicted patient to a range of broader contextual issues in primary care.

The treatment programs selected for the preceptorship reflected the program's capacity to provide a wide range of practical clinical experiences. In the program's first year, 10 students were provided a structured learning experience in the treatment of drug abusing individuals at a designated treatment facility. During the initial training sessions, emphasis was placed on the special needs of women of childbearing age and high-risk youth. A two day orientation to the field of addiction medicine at the Morehouse School of Medicine in Atlanta, Georgia. The "Introduction to Chemical Dependency" included presentations on Pharmacology, the Epidemiology of Substance Abuse, HIV Disease and Substance Abuse, Prevention and Treatment of Substance Abuse in Ethnic communities, Co-Morbidity, Diagnosis, Treatment Models, Prophylaxis Treatment of HIV Disease and other discussions of the physical and behavioral effects of various drug types. This program will be expanded in FY 1991 through a collaborative effort with the ADAMHA Institutes. OTI anticipates expanding the program to include other disciplines such as social workers, nurses, psychologists, and ministers.

CENTERS FOR DISEASE CONTROL
CENTER FOR ENVIRONMENTAL HEALTH

Minority Health

Minority Populations

Projects were implemented for the prevention of disabilities including developmental disabilities, injury disabilities from head and spinal cord trauma, and secondary disabilities. Surveillance activities and planned community programs for the prevention of primary and secondary disabilities will assess the disproportionate incidence and prevalence for specific disabilities among minority populations and the poor, and will give attention to the design of community-based prevention interventions to address those issues.

Surveillance, epidemiologic studies, and interventions for birth defects (including fetal alcohol syndrome) and developmental disabilities (including mental retardation) are being continued, as well as studies of potential environmental causes of low birth weight. These efforts are being conducted in a multiracial population that includes a large portion of blacks.

The Medical Examiner/Coroner Information Sharing Program, a surveillance system based on medical examiner/coroner (MEC) cases, involves a nationwide network of MECs to collect uniform and timely data on unanticipated deaths (such as homicides, suicides, unintentional injuries, acute poisonings, sudden infant death syndrome, deaths from disasters, and drug overdoses), and seeks to develop better ways of sharing information among MECs, the public health community, and other interested groups, especially minorities.

CDC's natural disaster emergency response plans were thoroughly tested with the occurrence of hurricane Hugo, which devastated St. Croix in the Virgin Islands and severely damaged parts of Puerto Rico and North and South Carolina; and an earthquake which destroyed bridges, highways, and buildings in the San Francisco Bay area. These two disasters resulted in considerable morbidity and mortality among minority populations, and we are hopeful that the epidemiologic studies being conducted will yield useful information to help minimize similar outcomes in the future.

CDC provides external quality assurance for neonatal screening for congenital hypothyroidism, phenylketonuria, and galactosemia. CDC is implementing a similar program for sickle cell disease, which is a significant disease in blacks. CDC has a major program in improving the laboratory measurement of cholesterol and other lipids which are important in diagnosing and treating cardiovascular disease. This program is of particular importance to blacks because cardiovascular disease is more prevalent in that population than in the white population.

In the Third National Health and Nutrition Examination Survey (NHANES III, 1988-1994), CDC is characterizing the exposure of the general U.S. population to lead and cadmium. Lead exposure is higher in blacks than other races. This survey will identify the extent of current lead exposure in whites, blacks, and Hispanics, and determine groups that should be special targets of prevention efforts. Also, in NHANES III, measurements are being made which characterize the nutritional status of whites, blacks, and Hispanics.

Several important efforts of the Center for Environmental Health and Injury Control (CEHIC) lend strength to our overall outreach to minorities. The Advisory Committee on Injury Prevention and Control has recommended that there be increased attention to intentional injuries which have a disproportionate impact on minorities. Likewise, in developing the Year 2000 Objectives greater emphasis has been placed on controlling violent and abusive behavior. In addition, a National Academy of Science Panel on Violence is exploring ways of understanding and controlling violence. In FY 1989, CEHIC supported an American Medical Association Conference on family violence, a problem which takes a heavy toll on the poor and minorities. CEHIC also provided support in FY 1990 for a conference to specifically address violence and public health.

CEHIC will continue to address fatal injuries that exact a disproportionate burden on minorities as compared with whites. CEHIC projects in support of points 1, 3 and 6 of the Secretary's Health Promotion Initiative include:

General

Injury Atlas

Mapping is a useful tool for identifying counties and regions of and regions of the country with high rates of injuries. The purpose of this project is to provide a visualization of geographic patterns of deaths associated with selected intentional and unintentional injuries using county-level color maps of the United States. Mapping of rates (per 100,000 population) will consider differences by age, race, and sex. The atlas will also provide age-specific rates of injuries by race (white and other) and sex, and age-adjusted rates by year of death, race, and sex. Approximately \$104,000 was spent on this project in FY 1990.

Indian Health Service Interagency Agreement with CEHIC is an effort to develop, implement, and evaluate injury control demonstration projects. Central to this Agreement is the Model Community Injury Control Project designed to establish model injury surveillance and injury control programs in three IHS Service Units: Cherokee, North Carolina; Rosebud, South Dakota; and Sells, Arizona.

California

The Southern California Injury Prevention Research Center (SCIPRC) is focusing on the problem of injuries in targeted high risk populations. The SCIPRC is studying intentional and unintentional injuries in ethnic/racial minorities, socioeconomically disadvantaged and other under-served populations in Southern California. Specific aims will include interdisciplinary research on injury causes, prevention and control in ethnic minority, disadvantaged, or under-served populations.

Los Angeles, California-Epidemic Aid, "Youth Homicide"

In May of 1988, the Los Angeles Police Department, contacted CEHIC about an increase in the numbers of youth homicides, particularly in the South-Central region of Los Angeles. From 1986 and 1987, homicides involving victims 10 to 19 years of age increased by 39% in the four county health districts serving this part of the city. Although the common perception in the community is

that many of the homicides may be involved which need to be addressed. In 1987, there were 32 homicides in Los Angeles involving victims less than 18 years of age which classified as gang homicides. Through October of 1988, there had been 36 such homicides.

Florida

Miami Falls Study will determine the epidemiologic characteristics of elderly fallers, environmental and host risk factors associated with falls, possible control measures, and the effectiveness of control measures in reducing morbidity, mortality, and medical costs. The surveillance phase, begun in June 1985, includes all falls reported by hospitals, the ambulance service and the medical examiner among persons 65 and over in four-census tracts of South Miami Beach, Dade County, Florida. The case-control study begun in January 1987 is comparing 600 surveillance cases with 800 population-based controls.

Georgia

Family and Intimate Assault in Atlanta (FINAA)

Physical violence between individuals who are related, who share the same household, or who are intimate with each other, is increasingly acknowledged as a serious social and health problem. Little is known about the characteristics of perpetrators, the victims, their families and their patterns of involvement with health, social, and criminal justice agencies. The FINAA project is a retrospective study of records to examine fatal and nonfatal assaultive injuries among family members and intimates in Atlanta, Georgia. The project is designed to describe previous agency contacts and make recommendations for providing services related to family and intimate assaults.

Maryland

Maryland State Health Department is assisting Baltimore City in developing a violence prevention and surveillance system for non-white males (15-34 years of age). Firearms are the leading cause of death for this target group.

Minnesota

Minnesota Department of Health is conducting a Positive Parenting Intervention to assess and propose interventions for families at high risk for child maltreatment, targeted in part to Blacks and Native Americans where homicide rates are elevated.

Missouri

Missouri Department of Health is creating an injury control unit within the Division of Health Resources. Intervention activities will address Black homicides, poisoning, and head and spinal cord injuries.

Kansas City, Missouri Health Department is working with an inner-city community based anti-crime organization, the Ad Hoc Group Against Crime, to establish an interpersonal violence reduction project in cooperation with the Kansas City, MO, Human Relations and Police Departments. The group will

identify high-risk youth and adults who have been involved in violent disputes to supplement actions taken by other agencies (e.g. medication, probation, suspension, etc.) with conflict resolution skills (which includes anger control and problem solving) be targeted toward the groups identified in Ad Hoc's homicide males between the ages of 17 and 29 who have a prior history of arrest for interpersonal violence and/or weapons charges. Referrals will be accepted from schools, youth serving agencies, police, the juvenile justice system, parents and courts. In addition outreach workers will make additional referrals, contact adult subjects and parents of troubled youth to obtain their cooperation, and follow up at regular intervals to monitor results.

New York

New York City Health Department is focusing on Minority Populations in the Central Harlem area. Intervention activities are addressing pedestrian and intentional injuries.

North Carolina

North Carolina Department of Human Resources is expanding the capacity of the Division of Health Services to address the problems of intentional and unintentional injuries with particular emphasis on high risk populations and injury prevention strategies in a rural setting.

Pennsylvania

The Philadelphia Injury Prevention Program (PIPP) is developing a model of a feasible injury prevention program in a predominantly black neighborhood that can be implemented in urban areas. The Safe Block Project is a community - based controlled trial that includes block wide home inspections, modifications and home educational activities.

Texas

San Antonio Metropolitan Health District will perform "appropriate interventions" in Hispanic and non-white populations, targeting homicide.

Washington

Washington State Department of Social and Health Services activities include prevention priorities in motor vehicle crashes, suicide, falls, drownings and poisoning among the elderly, children and poor.

CENTERS FOR DISEASE CONTROL
OFFICE OF THE ASSISTANT DIRECTOR FOR MINORITY HEALTH

Minority Health

The Office of the Assistant Director for Minority Health serves the Centers for Disease Control (CDC) by advising the Center's Director in the determination of the overall CDC policy and planning on minority health; provides leadership in assisting CDC's centers, Institutes, and Program Offices (CIO's) in identifying minority health problems and issues, and defining appropriate interventions; develops and enhances external contracts regarding minority health issues; coordinates and provides leadership for CDC's participation in PHS and DHHS minority health programs and activities; and assists CIO's and staff offices with programs and activities that have, or should have, special impact on minority health problems.

CENTERS FOR DISEASE CONTROL
OFFICE OF THE DIRECTOR/HUMAN IMMUNODEFICIENCY VIRUS

Minority Health

Directly Targeted Human Immunodeficiency Virus

In fiscal year 1989, an office on minority health activities (HIV) was established and staffed at CDC to ensure that HIV prevention programs are targeted to minority populations and that technical assistance is provided in the implementation of those programs.

In fiscal year 1987, CDC began specifically targeting funds to address HIV infection among racial and ethnic minority populations by awarding more than \$7 million to 41 State and local health departments to support community-based initiatives to prevent infection among minorities at risk for HIV infection. Approximately \$15 million was awarded to 52 State and local health departments for similar initiatives in fiscal year 1990 and approximately 315 CBOs serving minority populations were subsequently funded.

In fiscal year 1990, CDC also provided more than \$17 million directly to 98 community-based minority organizations in the metropolitan areas having the largest number of reported AIDS cases.

In addition, CDC awarded cooperative agreements to 23 national organizations to help schools and other agencies serving youth provide effective education about HIV. Of the 23 national organizations funded, five specifically targeted their efforts toward black and Hispanic youth. CDC also provides funds to the Indian Health Service for HIV prevention efforts directed to youth.

In fiscal year 1990, the CDC awarded more than \$6 million to 32 national and regional minority organizations to assist in developing special approaches to racial and ethnic minority populations and expanding public information efforts directed towards minorities.

Funds are also being provided to the United States Conference of Mayors (USCM) to support HIV information exchange and to expand funding to minority-oriented, community-based organizations (18 in 1990) interested in conducting HIV information programs.

Direct assistance will continue to be provided to minority organizations in the metropolitan areas having the highest incidence of AIDS among minorities. Support will also be provided to 10-15 minority organizations to develop and conduct training for local minority groups involved in HIV prevention activities. Efforts to control sexually transmitted diseases (STDs) in inner cities will be strengthened to reduce the risk of HIV transmission associated with genital ulcers and other STDs. Behavioral studies of risk factors and interventions will be conducted.

CENTERS FOR DISEASE CONTROL
CENTER FOR ENVIRONMENTAL HEALTH AND INJURY CONTROL

Minority Health

Childhood Lead Poisoning Prevention

In March, 1990, Dr. James O. Mason, Assistant Secretary for Health, U.S. Department of Health and Human Services, requested that the Committee to Coordinate Environmental Health and Research Programs develop a Strategic Plan for the Elimination of Childhood Lead Poisoning. This plan has been completed and is undergoing clearance through the Department of Health and Human Services.

In FY 1990, grants were awarded to six states and one city with demonstrated severe childhood lead poisoning problems for comprehensive screening and follow-up programs. CDC has continued to provide technical assistance to both funded and nonfunded programs. The CDC statement Preventing Lead Poisoning in Young Children, providing guidelines for screening children for lead poisoning and follow-up of children with elevated lead levels for pediatricians and screening will be published in 1991.

CDC, with the Health Resources and Services Administration and the University of Wisconsin, continues to administer a Blood Lead and EP Proficiency Testing Program. The Blood Lead Laboratory Reference System, a laboratory-based program, is being developed to improve the quality of blood lead measurements performed by lead poisoning prevention programs by providing technical assistance, consultation, reference materials and standards, and quality control samples. In addition, CDC is developing a user-friendly software package for use by childhood lead poisoning prevention programs. This software will serve as a program management tool, as well as allow some evaluation of the collected data. Further, CDC is working to develop ongoing national surveillance for elevated blood lead levels. In FY 1990, cooperative agreements have been awarded to five States to develop surveillance for elevated lead levels in both workers and children.

CDC is also working with the Association of State and Territorial Public Health Laboratory Directors and the Council of State and Territorial Epidemiologists to develop computer systems for laboratory data on blood lead levels for both public and private laboratories. These systems will also serve as an important source of surveillance data. CDC has been conducting epidemiologic studies related to lead since the 1970s. Recent studies include evaluations of exposure to lead-contaminated soil in Skagway, Alaska, and lead-contaminated water on the island of Hawaii; evaluations of lead exposures from backyard battery plants in Jamaica; and evaluations of screening program data in Chicago and New York City. CDC continues to investigate and report unusual sources of lead exposure, such as intravenous methamphetamine and folk remedies. Several planned studies include evaluations of ways of improving efficacy of screening and further examination of the efficacy of abatement in reducing children's blood lead levels.

CDC is also conducting NHANES III, a survey of a nationally representative sample of the U.S. population and an evaluation of numerous indicators of health. Blood lead and EP levels are measured in a subsample of the survey.

and are currently the only national data on blood lead levels in the U.S. population. Collection of samples is currently ongoing and will be completed in 1994. CDC also performs the laboratory analysis of blood lead and EP levels in the NHANES samples. CDC is developing the announcement for a Cooperative Research and Development Agreement with private industry to stimulate the development of improved instruments for blood lead measurements to be used in screening programs.

CENTERS FOR DISEASE CONTROL
CENTER FOR PREVENTION SERVICES

Minority Health

Sexually Transmitted Disease

Poverty and near-poverty appear as underlying elements of many health problems experienced by most minority populations in the United States. Blacks make fewer annual visits to physicians than whites, and black mothers are twice as likely as white mothers to receive no health care or care only in the last trimester of their pregnancies. Like black Americans, Hispanic Americans receive less preventive health care, including prenatal care, than the total population. In 1987, 13 percent of Hispanic mothers had late or no prenatal care compared to 4 percent of non-Hispanic whites.

Chlamydia prevalence, like most STD, is higher among minority populations. Gonorrhea rates continue to be high among blacks and are more than 50-fold higher than rates among whites. Minority women are more severely affected by PID and the complications of this disease. The proportion of women who report having received treatment for PID is higher among blacks (17 percent) than among whites (10 percent). Although PID hospitalization rates declined for both white and minority women in all regions, and for all age and racial groups during the 1980s, the rate remained 2.7 times higher for minority women.

Primary and secondary syphilis rates have decreased steadily among white men since 1982 to 2.8 per 100,000 in 1989. This decrease was due in large part to favorable changes in sexual behavior among homosexual men in response to the AIDS epidemic. In contrast, rates among black men have increased 152 percent from 63.2 per 100,000 in 1984 to 145.2 in 1989. Rates among black men were nearly 52 times higher than among white men in 1989. Although rates in Hispanic men have declined in the past two years, they remain nearly 10 times higher (27.3 per 100,000) than for white men.

Primary and secondary syphilis rates among black women have increased even more dramatically; rates increased 192 percent from 33.3 per 100,000 in 1984 to 97.2 in 1989. Rates among women in other race/ethnic categories decreased or remained at low levels during the same period. An important contributor to this rise apparently has been the exchange of sex for drugs. The increasing syphilis rate in this population has important implications for intervention. Health education and risk reduction messages have not yet effectively reached or been adopted by low-income minority populations.

Syphilis research has become increasingly important in recent years as a result of the current epidemic among minority heterosexuals and emerging links with HIV infection. Questions about the efficacy of current therapy, especially in HIV-infected persons, and the role of syphilis as a cofactor for HIV transmission have important immediate implications.

Cervical cancer has been linked to infection with Herpes simplex virus (HSV). Cervical cancer accounts for over 4,500 deaths in women each year in the United States. When adjusted for age, cervical cancer mortality rates are nearly three times higher among black women than among white women. Trichomonas infections are also more frequent among black women.

The rate of AIDS among blacks is more than three times that of whites. Among women and children, the gaps are even wider. Black women face between 10 and 15 times the risk of AIDS compared to white women. Black children account for more than 50 percent of all children with AIDS. The proportion of AIDS cases associated with intravenous drug abuse is greater for blacks than for other AIDS victims; higher rates of heterosexual transmission of the virus and transmission of the virus from mother to infant occur as a consequence. As with black Americans, HIV transmission among Hispanic women is primarily linked to intravenous drug abuse by these women or their sexual partners. A major objective of the Division of Sexually Transmitted Disease, CDC, is to develop effective and culturally relevant programs to inform and educate the general public, particularly members of minority populations, to gain broad support and acceptance of STD prevention program efforts throughout the U.S. and its territories.

Although not specifically targeted to minorities, project grants awarded to State and local health departments and appropriate public and nonprofit entities emphasize the reduction of morbidity and mortality from STD, particularly in minority inner-city, heterosexual populations -- the same groups that are at high risk of HIV infection associated with IV drug abuse.

In FY 1990, STD prevention and control activities for minority populations included the involvement, through grants to States and direct funding, of almost 400 Community Based Organizations who represent and serve culturally diverse populations.

CENTERS FOR DISEASE CONTROL
CENTER FOR PREVENTION SERVICES

Minority Health

Immunization

The Division of Immunization does not presently collect specific data on minority health students and schools. However, the delivery system of the public health agencies is primarily focused toward that population that would be considered less able to afford the services of the private medical system. The immunization status of children entering the nation's school systems is at an all time high, with 98 percent of the children in the kindergarten/first grade vaccinated against measles, rubella, and mumps. Ninety-seven percent of these children have received 3 or more doses of polio and DTP/Td/DT.

There are a few pockets of low immunization levels in the preschool population residing in the low income, urbanized areas of the Nation: these levels may be as low as 50 percent. The overall immunization level in the preschool population is estimated to be 70 percent to 80 percent.

During FY 1991 the Division of Immunization is conducting, through the National Health Interview Survey, an assessment of National and State specific immunization levels including levels at 2 years of age. In 1991, the Division will seek recommendations on how to best obtain an assessment of the immunization status in a low-income, urbanized area, with the purpose of developing a model that can be used in future assessments of similar areas.

In 1992, emphasis will be placed on implementing the successful approaches for raising the age-appropriate immunization levels of our nation's children, particularly the hard to reach populations in large, inner-city areas. This will include demonstration outreach projects to evaluate linking/coordinating immunizations with low-income service programs such as AFDC, Medicaid, and WIC. An estimated \$9.3 million will be devoted to these activities in 1992 to improve the health of minority children. Other services such as providing vaccine, disease and adverse event surveillance, measles outbreak control, and other immunization related services, totaling an estimated \$78.7 million, will also help improve the health of minority children.

CENTERS FOR DISEASE CONTROL
CENTER FOR INFECTIOUS DISEASES

Minority Health

Hepatitis B

Hepatitis B virus (HBV) infection is a serious problem in many areas of the world. In most of Asia, Africa, the South Pacific, the Amazon region of South America and parts of the Caribbean the chronic HBV infection rate exceeds 8% while in other parts of the world such as eastern Europe, the chronic infection rate exceeds 2%. In the United States, high infection rates are retained by these ethnic groups, especially persons who have recently immigrated to this country. In addition, there is a disproportionately high incidence of hepatitis B among Alaskan natives, Pacific Islanders, blacks and Hispanics. These ethnic group specific rates of chronic infection are also reflected in the rates of primary hepatocellular carcinoma (PHC) in the US.

An especially high rate of infection is observed in children born to foreign-born Asian mothers. There are an estimated 96,700 infants born to Asian immigrants or refugees in the US each year. Of these, 8,500 (9.0 %) will be born to positive mothers and these infants should be identified by the currently funded hepatitis B perinatal screening and treatment program. However, of the remaining 88,200 infants, it is estimated that 22,050 (25%) will become infected with HBV by five years of age and 5,513 children will remain chronically infected. It is these 88,200 infants for whom the ACIP recommends universal hepatitis B immunization. It is estimated that 75% of these children receive their childhood immunizations in the public sector at an estimated cost of vaccine of \$35 per child.

Currently, Alaskan Natives infants are routinely immunized through a program funded by the Indian Health Service. In western Pacific islands under US jurisdiction (American Samoa, Guam, Commonwealth of Northern Marianas (Saipan), Republic of Palau, Federated States of Micronesia, Republic of Marshall Islands), approximately 7% of the population chronically infected with hepatitis B virus. Universal hepatitis B immunization demonstration programs were begun in American Samoa in 1985 and in the remaining islands in 1988. Continued funding of this universal immunization program is required to assure continued prevention of chronic HBV infection. Infants of foreign-born Asian mothers are not routinely immunized at this time according to the current ACIP recommendations .

CENTERS FOR DISEASE CONTROL
CENTER FOR PREVENTION SERVICES

Minority Health

Tuberculosis

Tuberculosis in the United States is predominantly a disease of the socioeconomically disadvantaged, the elderly, and the foreign-born. Among minorities, it is primarily a disease of young adults. Of the 23,495 tuberculosis cases reported to CDC in 1989, over 15,000 or 67 percent occurred in racial and ethnic minorities, including 37 percent in blacks, 17 percent in Hispanics, 12 percent in Asians/Pacific Islanders, and 1.5 percent in American Indians/Alaska Natives. Relative to the incidence rate of 4.0 per 100,000 in non-Hispanic whites, the incidence in Asian/Pacific Islanders was 10-fold higher; in non-Hispanic blacks, 7-fold higher; in Hispanics nearly 5-fold higher, and in American Indians/Alaska Natives, 5-fold higher.

Although not specifically targeted to minorities, cooperative agreements awarded to State and local health departments emphasize the reduction of morbidity and mortality from TB in high-risk groups, particularly in racial and ethnic minority populations.

CENTERS FOR DISEASE CONTROL
CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION

Minority Health

Early Detection of Breast and Cervical Cancer

Efforts to decrease morbidity and mortality from breast and cervical cancer, through the development and implementation of comprehensive screening programs, are currently underway. Breast and Cervical Cancer Mortality Prevention Act of 1990 funding will initiate efforts that are directed toward targeted populations, including black and native American women. Activities will include the following: (1) payment for breast and cervical cancer screening for women where cost is a barrier to obtaining these services; (2) screening tests; (3) education of the public about the need for routine screening; (4) education of health care providers about recommended screening guidelines; and (5) assurance of the quality of the screening tests.

CDC will implement the following activities in FY 1991 to address the principal components of a national program aimed at reducing or eliminating mortality from breast and cervical cancer: Development of a national plan for breast and cervical cancer control; assistance to States to conduct comprehensive breast and cervical cancer programs, especially those directed at women where cost is a barrier to obtaining needed service; and development, implementation, and evaluation of strategies to increase and improve public and professional awareness of the problems which result in excess mortality from these cancers.

CDC is nearing completion of the final draft of a National Plan for Breast and Cervical Cancer Control. At the request of the Assistant Secretary for Health, CDC has worked with the other PHS agencies as well as representatives from a variety of professional and voluntary health organizations and State and local health agencies to develop this plan. This plan, which will offer objectives as well as recommended actions, will form the framework for coordinated activities from numerous governmental and non-governmental organizations.

States will implement comprehensive programs to include both direct and follow-up services. The direct service component will be initiated Statewide during the current year and focus on women at risk. Amount of funding varies from State to State, with approximately \$3-4 million for each State. During the year, three to five new States will be selected for funding while four States (Colorado, Minnesota, South Carolina, and West Virginia) will continue their comprehensive screening programs, including the direct service component. During FY 1991, a total of approximately seven to nine States will have implemented comprehensive screening programs. The CDC is required to utilize 80% of its appropriation for State-based programs that include provision of screening and follow-up services. States are required to utilize 60% of the funds to actually provide these screening and follow-up services. A match of \$1 of State funds for every \$3 of Federal funds is now required.

CDC will also work with other organizations, such as the American College of Radiology, the National Medical Association, and the Colorado AMC Cancer Center, to assist in developing plans and methods to improve public and

professional awareness of these cancers as well as to investigate the issues related to quality assurance for screening tests. These efforts will result in the development of products to implement more effective control programs that reach a wider population of women in need of screening.

In 1992, \$50 million will be directed to support State health departments in the development and implementation of comprehensive breast and cervical cancer control programs and the establishment of key components which will provide the foundation for a strong national effort to reduce mortality from these cancers. Approximately \$40 million (80%) will be directed to State health departments for the operation of their comprehensive programs. This includes resource assistance to the States funded in FY 1991 to enable them to increase the number of women obtaining services through the programs as well as awards to one or more additional States.

CENTERS FOR DISEASE CONTROL
CENTER FOR ENVIRONMENTAL HEALTH AND INJURY CONTROL

Minority Health

Injury Control

The impact of injury on Americans demands an extraordinary effort. Over 150,000 injury deaths occur each year, including over 52,000 due to violence; 48,000 related to motor vehicle crashes; 40,000 unintentional injury deaths from such causes as fires, burns, falls, drowning, and poisonings; and 10,000 work related deaths. Injury is the leading cause of years of potential life lost and the fourth leading cause of death. Blacks and other minorities are affected disproportionately in relation to the white population, particularly by intentional injury. In 1985, when the lifetime cost of injury was estimated at 158 billion dollars, injuries cost the Federal government 21.7 billion dollars (i.e., 8.9 billion dollars in direct medical payments, 12.8 billion dollars in disability and death payments). While injury far outranks other diseases and conditions in both years of life lost and cost, money spent on injury research is far less than what is spent on other health problems.

In a 1985 report, titled Injury in America, the National Academy of Sciences recommended that the Centers for Disease Control's (CDC's) Injury Control Program have the leadership role of coordinating Federal efforts in injury control. The House Appropriations Committee restated its recommendation in the Committee Report that accompanied the House Appropriation Bill for Fiscal Year 1989 (report 100-689).

CDC's Injury Control Program approaches the problem by dividing injury into three phases: Prevention, Acute Care, and Rehabilitation. Epidemiology, one of CDC's traditional strengths, and biomechanics, a fundamental science of injury control, are applied in each of the three phases. Biomechanics is critically important in reducing injuries from motor vehicle crashes, which cause almost a third of all injury deaths. CDC's approach to injury control includes the development of research and interventions for the acute care and rehabilitation phases as well as the prevention phase of the injury problem. For each of the three phases, the Injury Control Program supports grants to build the capacity of State and local health departments and conduct extramural research, as well as carry out intramural research and program activities.

The Injury Control Program supports three mechanisms for extramural research.

1. Injury Control Research Centers (ICRCs): there are currently eight ICRCs receiving funds through the grant award process. An ICRC is usually established in an academic institution and works toward the development of interdisciplinary, comprehensive approach to address multiple aspects of the injury problem. The research being done in the centers includes motor vehicle injury control, the prevention of childhood injuries, injury control policies, acute care, and rehabilitation. When possible, those centers relate to other prevention centers and highway traffic safety centers.

2. Research Projects: There are currently 37 individual research projects receiving funds through the grant awards process. Research projects have a

narrower focus than ICRCs and are designed to determine what causes an injury, or to identify interventions to prevent injuries, or to evaluate the effect of an intervention.

3. Research Program Project Grants (RPPG): The RPPGs represent a new category of research grants and two awards were made during FY 1990. The RPPGs fall between ICRCs and research project grants in scope. Recipients will generally be academic institutions with a cluster of research projects focusing interdisciplinary resources on a particular aspect of injury control, such as acute care or biomechanics, or in a major cause of injury, or major population segment effected by injury.

In a type of extramural activity more familiar to CDC, the Injury Control Program provides grants and works with State and local health departments to build their capacity to control injuries and to evaluate interventions. These control activities are used to immediately transfer the technology that is found effective by the research activities into practice. Three different types of grant awards have been made to State and local jurisdictions.

1. Fifteen grants have been awarded to State and local health departments to build overall capacity in injury control.
2. Seven grants have been awarded to States to develop injury surveillance programs.
3. Six States and local health departments have received funding to implement and evaluate specific injury interventions.

CENTERS FOR DISEASE CONTROL
CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION

Minority Health

Infant Mortality

CDC conducts surveillance and epidemiologic investigations, and provides program development and technical assistance, to reduce perinatal, neonatal, and postneonatal mortality and morbidity related to low birth weight, sudden infant death syndrome (SIDS), prematurity, congenital defects, and complications of pregnancy. In partnership with States, efforts are directed at reducing adverse pregnancy outcomes by identifying risk factors and developing and evaluating interventions to target these factors. Analytic support is provided to link birth/death certificates with key Maternal and Child Health (MCH) Program data to permit monitoring of program coverage, targeting, and effectiveness.

CDC Infant Health Initiative Activities

I. Surveillance

To help States better address the infant health issues outlined above, a comprehensive surveillance system has been initiated to (a) identify those populations at highest risk, (b) enable States to target their intervention efforts, and (c) provide a data resource for evaluating progress toward the Year 2000 Objectives related to low birth weight and infant mortality. Two substantial surveillance enhancements to better address these infant health issues have been initiated in recent years:

- o Pregnancy Nutrition Surveillance System (PNSS): an ongoing program-based surveillance system designed to monitor the prevalence of nutrition-related problems and behavioral risk factors among high-risk prenatal populations. This effort, initiated in 1979, is designed to improve the management of State prenatal programs. To be expanded in selected States in 1991 and 1992.
- o Pregnancy Risk Assessment Monitoring System (PRAMS): initiated in Fiscal Year 1987. PRAMS is State-based surveillance of maternal behaviors during pregnancy and the child's early infancy. It is being carried out through cooperative agreements in Indiana, Maine, Michigan, Oklahoma, West Virginia, and the District of Columbia. In addition, PRAMS project staff are providing technical assistance to the States of Alaska and California as these States implement PRAMS with their own resources. In 1991 and 1992, will be expanded from 8 States to a total of approximately 26 States.

PNSS and PRAMS are significantly increasing the capacity of States to monitor health-related behaviors associated with poor pregnancy outcome, use the information to direct intervention efforts more precisely and efficiently to areas and populations in greatest need, and maximize the use of readily available clinic information for programmatic purposes.

II. Research into the Black/White Gap in Infant Mortality

In FY 1991 and FY 1992 CDC is expanding research activities on racial disparities in infant mortality and low birth weight to include a study of pregnancy outcome among black and white enlisted women in the military. A second focus of research will involve studies that will examine psychosocial and physiologic effects of being Black in the U.S. on pregnancy outcome.

III. State Capacity Building for MCH Epidemiology and Surveillance

Maternal and Child Health Epidemiology Program: Because programs to reduce infant mortality are implemented at the State level, an essential CDC function is to improve the State capacity to conduct surveillance, investigations, program evaluation, and prevention efforts, as well as improve service delivery. CDC provides technical assistance for States to target and effectively serve high-risk groups. The Maternal and Child Health Epidemiology Program (MCHEP) was developed and implemented in collaboration with the Health Resources and Services Administration. Over the past 5 years, long-term support has been provided to five States (Mississippi, Alabama, South Carolina, Georgia, California) and the Commonwealth of Puerto Rico through the assignment of epidemiologists to work with maternal and child health directors. Short-term assistance has been provided to New York City, New Jersey, Kentucky, West Virginia, Arkansas, Iowa, Hawaii, Montana, Utah, Puerto Rico, and the District of Columbia.

Centers for Healthy Infants and Pregnancies: Using resources from the 1991 Infant Health Initiative, CDC will initiate a new expanded program of technical assistance to States in 1991 through the development of Centers for Healthy Infants and Pregnancies (CHIPS) in selected States. CHIPS will provide an opportunity for State health departments to work with CDC and other local, State, federal and private organizations to formulate appropriate goals and objectives, conduct surveillance and epidemiologic investigations and evaluations of reproductive health problems, develop and implement effective interventions, conduct evaluations of service programs, and build capacity in States to conduct surveillance and research and translate surveillance and research findings into effective interventions.

IV. Prenatal Smoking Cessation Projects

The Prenatal Smoking Cessation (PSC) projects are designed to share the experiences gained by CDC personnel from CDC demonstration projects and other trials in planning, implementing, and evaluating prenatal smoking cessation programs in State and local health departments. For example, the Smoking Cessation in Pregnancy Research and Demonstration (SCIP) project, a program of assistance to the States of Colorado, Maryland, and Missouri to develop new smoking cessation interventions for pregnant women, has enabled the following accomplishments:

- o State-of-the-art interventions have been developed that require no additional staff to implement, and include patient counseling at every visit, self-help materials, and individual guidance identifying support for stopping smoking. Urinary cotinine tests are being performed to biochemically validate each woman's smoking status at the three study points.

Preliminary results from two States are encouraging: women attending intervention clinics are more likely to quit smoking by the 8th month of gestation than women attending control clinics (Colorado: 13.8% of women in intervention clinics quit smoking versus 9.5% in control clinics; in Missouri these rates were 14.4% versus 10.6%).

- o States are committed to continuing the smoking cessation interventions after the demonstration phase, extending the program to include those clinics now serving as controls.

The process of technology transfer for prenatal smoking cessation activities includes five phases: needs assessment, program development, program implementation, program evaluation and program maintenance. It is anticipated that each State participating in PSC will develop a fully operational, Statewide prenatal smoking cessation activity as part of their on-going maternal and child health care delivery system.

Currently, CDC has provided technical assistance in prenatal smoking cessation to Idaho, South Dakota, California and Maine. Plans for FY 1991 and FY 1992 call for the expansion of PSC to a total of approximately 16 additional States over the two year period.

Nutrition Status Assessment and Monitoring

Pediatric Nutrition Surveillance System: Poor nutrition and its effect on childhood morbidity, growth, and development is another important public health issue. There have been few data available on the extent, etiologies and risk factors associated with malnutrition (overnutrition as well as undernutrition) among children. This problem is further complicated by the lack of a satisfactory definition of malnutrition in the domestic setting. The longterm impact of childhood obesity on adult obesity is also not well-defined. Obesity is a particular problem among low income, ethnic minority populations, and the lack of an adequate reference for measuring the condition further complicates the degree to which the problem can be accurately defined. Most of the data currently available on childhood malnutrition and obesity are based on small case studies from which prevalence estimates cannot be made, nor can the determination of risk factors and etiologies.

In 1973, CDC developed a system for the surveillance of nutrition problems (anemia, underweight, overweight, low birthweight) among low income children coordinated through State health departments. Since then, the Pediatric Nutrition Surveillance System (PedNSS) has grown from an initial five States to the present 42 State participants, including the District of Columbia, Puerto Rico, Navajo Nation and other tribal programs. This system primarily uses data from children who participate in the Women, Infants, and Children Supplemental Food Program (WIC) and in other Maternal Child Health Programs which are targeted toward low income families. These data provide information to enable States to identify nutrition problems among children who participate in these programs, target interventions and monitor trends.

Lessons learned from a recently completed feasibility project to examine the surveillance of severe pediatric undernutrition will be used to enhance the

practical usefulness of the PedNSS in identifying these children. Information on risk factors for children who meet the case definition for severe undernutrition will assist States to promptly initiate early intervention. Successful strategies for detecting severe undernutrition among children in hospitals and other health and social service care facilities will be summarized and disseminated to States.

CENTERS FOR DISEASE CONTROL
OFFICE OF THE DIRECTOR/HUMAN IMMUNODEFICIENCY VIRUS

Minority Health

Indirectly Impact-Immunodeficiency Virus

In addition to those efforts which are specifically directed to minority populations, the CDC conducts many additional HIV prevention activities which also benefit minorities. For example, Perinatal AIDS Prevention Projects, TB/HIV Control Projects, Health Education/Risk Reduction, and Counseling, Testing, Referral and Partner Notification (CTRPN) Programs address high-risk populations which include minorities. Also, information/education messages directed to the public have minority components which are designed by minority advertising firms through subcontracts.

CENTERS FOR DISEASE CONTROL
CENTER FOR INFECTIOUS DISEASES

Minority Health

Infectious Diseases

Other infectious diseases of particular significance to minority populations include plague, dengue, sickle cell anemia, and Human Parvovirus B19 infections. Plague is an acute bacterial infection spread to humans by wild rodents and their fleas. The disease occurs most commonly in Hispanic and native American populations in Arizona and New Mexico. The major efforts to educational programs targeted to Hispanic populations and native American tribes in the southwestern United States. Epidemic dengue and dengue hemorrhagic fever, transmitted by the Aedes Aegypti mosquito, are a major disease problem in Puerto Rico and throughout the Caribbean Basin. Ongoing programs for prevention and control of dengue include surveillance, mosquito containment initiatives, and widespread community education programs. Sickle cell anemia and human parvovirus B19 infections occur predominantly in blacks and Orientals. CDC involvement includes outbreak investigation and epidemiologic studies for a total of \$2,000,000.

CENTERS FOR DISEASE CONTROL
OTHER CHRONIC AND ENVIRONMENTAL DISEASE PREVENTION (CCDPHP)

Minority Health

Reducing Premature Death and Disability from Cardiovascular Disease

Cardiovascular disease resulted in 976,700 deaths in 1987, including 513,700 from coronary heart disease and 149,200 from stroke. To have a widespread impact on reducing cardiovascular disease (as well as other preventable chronic diseases) in the United States, we must apply the lessons learned from several major community trials, using community-based approaches to reducing modifiable behaviors that place individuals at increased risk for disease. The South Carolina Cardiovascular Disease Prevention Program serves as a learning laboratory for identifying successful strategies for implementing community-based interventions. Baseline, mid-course, and follow-up surveys of the population, community resource inventories, and several process evaluation studies have been completed. Public awareness events with local media have promoted targeted intervention activities, including physical activity campaigns, stop smoking campaigns, television home study course on the USDA nutritional guidelines, blood pressure and blood cholesterol screening, self-help kits for fitness, nutrition, and weight control, work site health promotion programs, walking trails, and training for health professionals on cholesterol control and smoking cessation.

The CDC is assisting several States to build their capacities to implement interventions targeted toward health behaviors in selected communities and to evaluate the impact of the programs. Heart health training for teachers, in-service education for physicians, and cholesterol screening have been implemented, with half of all intervention efforts directed toward high-risk, minority populations.

Involvement of Minority Communities in Health Promotion Programs

Health promotion activities among minorities and minority communities are being emphasized. For example, at least 50 percent of intervention efforts developed and implemented through CDC's Community Chronic Disease Prevention program are being targeted toward high risk, minority populations. Protocols for interventions incorporate community organization techniques tailored to minority communities. Increased attention is being given to the importance of the community's infrastructure and leadership and to the inclusion of a broad array of organizations in developing intervention protocols. Similarly, family values and the role of churches have also been emphasized.

Strategies to Combat Smoking Among Minorities

The CDC's Office on Smoking and Health has conducted a number of analyses of smoking behavior (initiation, current use, and quitting) by race. The Office also produces and distributes a series of racially sensitive television and radio public service announcements, as well as print materials.

CENTERS FOR DISEASE CONTROL
INDIRECT PROGRAMS

Minority Health

Preventive Health and Health Services Block Grant:

The preventive health and health services block grant provides States with funds for preventive health services, which reduce preventable morbidity and mortality and improve the quality of life. These grants give the States flexibility to decide how grant funds will be used within their State to meet their priorities in prevention. Within the block grant are funds expended to indirectly benefit minorities such as programs designed to reduce the incidence of chronic diseases.

Since these activities affect the total population of the United States, amounts for these programs are based on the percentage of the population that consists of minorities.

Prevention Centers:

Grants are made with academic health institutions to establish, maintain, and operate centers for research and demonstration for health promotion and disease prevention. These centers undertake research and demonstration projects in health promotion, disease prevention, and improved methods of appraising health hazards and risk factors, and serve as demonstration sites for the use of new and innovative research in public health techniques to prevent disease.

Since these activities affect the total population of the United States, amounts for these programs are based on the percentage of the population that consists of minorities.

Infectious Diseases:

CDC's efforts in infectious disease prevention focus on: research to develop new or improved diagnosis, prevention, and control methods and techniques; working with State and local health departments and private health-care providers to transfer and accelerate the general application of accepted prevention technologies; and maintaining a capability to respond to outbreaks of many diseases that seldom occur.

The major areas of concern supported by this activity include hospital infections, bacterial meningitis, pneumococcal disease, Lyme disease, tuberculosis, infectious diseases in child-care settings, foodborne diseases, opportunistic infections, and infectious diseases of minority populations.

Since these activities affect the total population of the United States, amounts for these programs are based on the percentage of the population that consists of minorities.

Other Chronic and Environmental Disease Prevention:

The CDC applies its environmental disease expertise in problem identification, intervention development and application, State capacity-building, technology transfer, and program evaluation to address the prevention of chronic disease, the reduction of premature death and disability associated with tobacco use,

the prevention of birth defects and developmental disabilities, the prevention and control of disabilities, prevention of adverse effects of lead poisoning, and the prevention of environment-related diseases. Prevention offers the major challenge and opportunity for averting a substantial portion of this unnecessary illness and death.

Since these activities affect the total population of the United States, amounts for these programs are based on the percentage of the population that consists of minorities.

Occupational Safety and Health:

The National Institute for Occupational Safety and Health in CDC is the Federal agency charged with conducting a national program of occupational safety and health research and dissemination. The purpose of this program is to do research and disseminate scientific and public health information necessary to ensure safe and healthful working conditions for the 124 million American working men and women.

Since these activities affect the total population of the United States, amounts for these programs are based on the percentage of the population that consists of minorities.

Epidemic Services:

The objectives of the epidemic services activity are to: provide for the prevention and control of epidemics and protect the civilian population from public health crises such as biological and chemical emergencies; maintain surveillance systems, analyze data, and respond to public health problems when indicated; train public health epidemiologists; and carry out the quarantine program as required by regulations.

Since these activities affect the total population of the United States, amounts for these programs are based on the percentage of the population that consists of minorities.

Health Statistics:

The National Center for Health Statistics (NCHS) is the nation's principal health statistics agency, mandated to monitor the nation's health and use of health services and to explore the relationships between risk factors and disease. A clear understanding of health problems and their impact on the population and economy serve as the foundation of the Nation's public health, health research, and health policy efforts. Health officials and researchers in CDC, the Department, State/Local governments, and the private sector rely heavily on NCHS data for fundamental measures of the nation's health.

Since these activities affect the total population of the United States, amounts for these programs are based on the percentage of the population that consists of minorities.

Human Immunodeficiency Virus:

HIV infection continues to be one of the Nation's major public health problems with an estimated 1,000,000 Americans already infected. CDC's mission is to prevent HIV infection and to reduce associated morbidity and mortality. CDC provides national and international leadership and scientific and technical assistance; develops guidelines; trains laboratorians and other health

workers; and provides financial and technical assistance to regional and national organizations, State and local agencies, and CBOs to carry out programs to prevent HIV infection. CDC's program primarily encompasses surveillance, population-based research, and information and education/preventive services. In addition, some emphasis is placed on specific areas of applied biomedical and behavioral research.

Since these activities affect the total population of the United States, amounts for these programs are based on the percentage of the population that consists of minorities.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Bureau of Health Professions

Minority Recruitment Activities

Minority recruitment initiatives were carried out among a number of the Bureau's training and grant programs in response to the national concern that minority groups continue to constitute a relatively small percentage of workforce in most health professions.

In FY 1990, 15 Area Health Education Center programs indicated efforts aimed at minority recruitment of health professionals. Ten of these programs received funds totaling \$512,300, which are estimated to affect 5,372 individuals. The University of Arizona received \$90,000 to support significant recruitment efforts.

Minority recruitment is being planned among six of the grantees under the new Health Education and Training Centers program. Four of the grantees received a total of \$464,162 for their efforts affecting 370 individuals.

Under the section 786(a) Family Medicine training programs, one predoctoral, five residency, and nine faculty development grantees reported minority recruitment activities. It is estimated that 6 minority residents and 84 minority faculty will benefit from support of this initiative. One Family Medicine Departments grantee estimated that support of recruitment efforts would benefit 5 students.

Twenty-one General Internal Medicine/General Pediatrics Residency program grantees have instituted minority recruitment activities affecting 15 trainees. The Milwaukee College of Medicine received \$7,750 specifically for their efforts. Six Faculty Development programs have also indicated minority recruitment activities, for which \$1,936 was awarded.

A total of \$545,067 was awarded among 20 of the 37 programs to train Physician Assistants who maintain emphasis on the recruitment and retention of minorities in their programs. An estimated 500 trainees will benefit from these efforts. The largest award was for \$142,180 to Howard University for developing a unique training program component using graduate mentors.

Three Preventive Medicine Residency Training grantees indicated involvement in minority recruitment for their programs.

Among the Geriatric Medicine and Dentistry Faculty Training projects supported during FY 1990, 16 will focus on the recruitment and training of 71 minority fellows.

Nine of the Podiatric Primary Care Residency program grantees received a total of \$44,688 for their minority recruitment and training initiatives affecting 41 residents.

Nursing Education Opportunities for Individuals from Disadvantaged Backgrounds

The objectives of this program are to increase nursing opportunities for individuals from disadvantaged backgrounds by identifying, recruiting and selecting such individuals; facilitating their entry into schools of nursing; providing counseling or other services designed to assist such individuals in completing their nursing education; providing, prior to entry into a school of nursing, preliminary education designed to assist them to successfully complete such regular course of education; paying such stipends; publicizing financial aid available to persons enrolled in schools of nursing; and faculty development by providing training, information, or advice to the faculty of such schools with respect to encouraging such individuals to complete the programs of nursing education in which the individuals are enrolled.

Centers of Excellence (COE)

The Centers of Excellence (COE) program strengthens the national capacity to train minority students in the health professions at a selected group of health profession schools. Its purposes are to establish, strengthen, or expand programs to enhance the academic performance of minority students attending the school; to establish, strengthen, or expand programs to increase the number and quality of minority applicants to the school; to improve the capacity of such schools to train, recruit, and retain minority faculty; to carry out activities to improve the information resources and curricula of the school and clinical education at the school with respect to minority health issues; and to facilitate faculty and student research on health issues particularly affecting minority groups.

The original Centers of Excellence were authorized under the Excellence in Minority Health Education and Care Act of 1987. Eligible institutions included four Historically Black Colleges and Universities (HBCUs) that had received a contract under section 788B of the PHS Act (Advanced Financial Distress Assistance) for FY 1987. In addition to the HBCUs being continued, Hispanic, Native American and Other Minority Health Professions Education Centers of Excellence were added through an amendment contained in the Disadvantaged Minority Health Improvement Act of 1990.

In FY 1991, under section 782, the "Programs of Excellence in Health Professions Education for Minorities, as amended by the Disadvantaged Minority Health Improvement Act of 1990", there is \$11.5 million available to continue the original Centers of Excellence Programs at Xavier University, School of Pharmacy; Tuskegee University, School of Veterinary Medicine; and Meharry Medical College, Schools of Medicine and Dentistry. There is also \$2.4 million available to establish Hispanic, Native American and Other Minority Health Professions Education Centers of Excellence. It is projected that six Hispanic Centers of Excellence and four Native American Centers of Excellence will be established. It is proposed that the Hispanic COEs have a minimum of 20-25 Hispanic students enrolled, and the Native American COEs have a minimum of 5-8 students enrolled. The Centers will be established in schools of medicine, dentistry, and pharmacy. Our budget request and justification for FY 1992 has also gone for this program.

Health Careers Opportunity Program (HCOP)

The Health Careers Opportunity Program awards grants to schools of medicine, osteopathic medicine, public health, dentistry, veterinary medicine, optometry, pharmacy, allied health, chiropractic, and podiatric medicine and public and nonprofit private schools which offer graduate programs in clinical psychology, and other public or private nonprofit health or educational entities to assist individuals from disadvantaged backgrounds to enter and graduate from health and allied health professions programs. It supports recruitment, education designed to expand the academic ability of disadvantaged students during their preprofessional training, and activities designed to facilitate their entry into health and allied health professions schools and enhance their retention potential in these schools through to graduation.

In FY 1991, under section 787, the Health Careers Opportunity Program is authorized \$36.0 million. The appropriation is \$31.5 million of which \$6.3 million is set aside for Financial Assistance for Disadvantaged Health Professions Students in schools of medicine, osteopathy, and dentistry. Another \$856,000 is deducted for evaluation and cuts authorized by Gramm-Rudman which leaves an available balance of \$24.406 million. Of this amount, \$19.0 million is committed to continue 124 grant programs which leaves \$5.3 million for competitive grants. It is projected that 40 competitive grant applications will be funded in FY 1991 which will total 164 active projects. The legislation for HCOP will expire at the end of FY 1991, therefore, there is no current authorization for FY 1992. Our budget request and justification for FY 1992 has gone forward for this program.

Exceptional Financial Need Scholarships (EFN)

In FY 1992, the Financial Assistance for Disadvantaged Health Profession Students program will be combined with the Exceptional Financial Need Program to present one effort directed at providing non-service conditional scholarships to disadvantaged and minority students. In FY 1992, \$16,981,000 is requested for the Exceptional Financial Need Scholarship Program.

HEALTH RESOURCES AND SERVICES ADMINISTRATION
Bureau of Health Professions

Hispanic Initiative

In 1985, Hispanic Americans were estimated to be 7.2 percent of the Nation's population. Many of them reside in rural areas or urban ghettos which are generally classified as medically underserved. It is interesting to note that despite the dramatic increase of Hispanics in this country, the ratio of health professionals to this population remains disproportionately low. Medical school entrants include only 4.2 percent Hispanic students, further frustrating the problem of training health professionals who are sensitive to the health and cultural needs of this population. The Bureau continues to fund through its grant programs, efforts to recruit and train Hispanic health professionals. Accomplishments for FY 1990 are as follows:

I. Area Health Education Center (AHEC) Program
(section 781)

It is not unusual that in those States which have a large Hispanic population as well as an AHEC program, that efforts to recruit and train Hispanics for the health professions are significant. A total of \$304,275 was requested by 9 of the 12 AHEC projects which specifically indicated efforts in this area. Over 2,556 individuals are estimated to be affected by these activities. The University of Arizona received the largest award (\$225,000) for its targeted activities to train health professionals who will develop services for Mexican Americans living in urban ghettos as well as the agricultural areas of Arizona.

II. Health Education and Training Centers
(section 781)

Two grantees under this new program received a total of \$756,014 for the development of health professions training and education for Hispanic populations. Approximately 1,249 individuals are expected to benefit from these efforts.

III. Family Medicine Training (section 785(a))

Three grantees under the Section 786(a) Family Medicine Graduate Training program reported activities targeted for Hispanics, which will impact six residents. One grantee received \$30,980 for initiatives in cross-cultural training.

IV. Physician Assistant Training Program (section 783)

Fourteen Physician Assistant Training program grantees reported activities which specifically benefit the Hispanic population (either through recruitment or curricular/clinical activities). An estimated 115 trainees will be affected. Total funds in the amount of \$30,950 were requested for these activities.

V. Podiatric Primary Care Residency Training (section 788(e))

The Illinois Masonic Medical Center received \$4,266 to provide training for three residents under their Hispanic initiative.

VI. Geriatric Medicine and Dentistry Fellowships (section 789(b))

Two grantees under this program have indicated training under this initiative for 11 fellows.

HEALTH RESOURCES AND SERVICES ADMINISTRATION
Bureau of Health Professions

Native American Indian Activities

In FY 1990, four of the Bureau's grant programs received a total of \$1,038,614 for education and training efforts specifically related to the health care of the Native American Indian population.

Seven of the Area Health Education Center (AHEC) grantees indicated a commitment to training in this area and received awards totaling \$378,500 estimated to affect 3,080 trainees and population. The largest award (\$250,000) was to the University of Arizona AHEC for their recruitment and training initiatives focusing on the Native American population in that region.

Native American populations will benefit from the education and training to be conducted under the new Health Education and Training Centers program. One project has received \$13,922 to develop a training program for 70 individuals.

Nineteen grantees indicated that their Physician Assistant Training programs would expose 48 students to the health care of Native American Indians, using such training modalities as clinical rotation on Indian reservations. A total of \$84,305 was requested by six of these grantees for program initiatives in this area.

Three Nursing Special Project grants totaling \$561,887 focus on the education of Native American Indians. Two projects focus on basic nursing education, the third on training trainees from American Indian nursing homes.

One section 786(a) Family Medicine Predoctoral training program grantee reported specific activity to benefit the Native American population.

One AIDS Regional Education and Training Center project will focus their training on HIV/AIDS issues relevant to the Native American population, from which 63 individuals will benefit.

NATIONAL INSTITUTES OF HEALTH

National Heart, Lung, and Blood Institute

MINORITY HEALTH AND ASSISTANCE TO MINORITY STUDENTS AND SCHOOLS

Minority programs supported by NIH are primarily in two areas: (1) research on diseases that disproportionately affect minority populations, and (2) assistance to minority investigators, students, and schools. These programs are targeted to four minority populations: Blacks, Hispanics, Native Americans, and Asian/Pacific Islanders.

The National Heart, Lung, and Blood Institute (NHLBI) has a long history of support for minority programs, including research, research training, and career development in the Institute's mandated disease areas.

Minorities Are at Higher Risk for Some Heart, Lung, and Blood Diseases

Cardiovascular Diseases -- Black females have higher rates of coronary heart disease (CHD) than white females. Blacks generally have a higher prevalence rate for angina and a higher rate of fatal heart attacks than whites. Studies indicate that Blacks in the United States have an increased risk of CHD due to hypertension, diabetes mellitus, certain cardiac abnormalities such as left ventricular hypertrophy (enlargement of the lower left heart chamber), and obesity (in Black women).

Hypertension is one of the major risk factors for cardiovascular disease (CVD) in Black Americans. Mean blood pressure levels are higher in Blacks than in whites, and more Blacks than whites have definite, borderline, and isolated systolic hypertension.

Although hypertension is less prevalent in Mexican Americans than in Black Americans, the rates are still higher than those for non-Hispanic whites, especially at the lower socioeconomic levels. Available data indicate that cardiovascular diseases are the leading causes of death in every minority group.

Lung Diseases -- Asthma is more severe in Blacks than in whites. Although asthma is only slightly more prevalent among Blacks than whites, Blacks are twice as likely as whites to be hospitalized, and are almost three times more likely to die from this disease than whites. Sarcoidosis, a chronic, progressive, and generalized disease that primarily affects the lungs, also is more prevalent in Blacks than in whites. Blacks are at least seven times more likely than whites to die of sarcoidosis.

Blood Diseases -- In the United States, sickle cell anemia, an inherited blood disorder, is predominantly found in people of

African ancestry. The incidence of sickle cell anemia in this group is approximately one in 500 at birth, affecting more than 50,000 individuals.

Patients with sickle cell anemia often experience a number of serious complications. Bacterial infections, especially *Streptococcus pneumoniae*, are a major cause of illness and death in young children. Stroke also is a significant problem, affecting 6 to 12 percent of patients. Other serious problems include recurrent episodes of pain, obstruction of pulmonary vessels, eye and kidney complications, cell death (aseptic necrosis) in the hip, and gallstones.

Cardiovascular Studies Focus on Various Minorities

One of the first major programs to investigate cardiovascular health in Blacks, the Evans County (Georgia) Study, began in 1957 and continues to this day. Landmark data obtained during the past 30 years on Black-white differences in coronary heart disease (CHD) and hypertension risk factors are derived from this study, in which one-third of the study population of 3,102 men and women is Black.

The Strong Heart Study, an epidemiologic study of cardiovascular disease in American Indians, began in 1988 and is the largest multicenter health study of American Indians ever undertaken. The study is evaluating morbidity and mortality data from medical records for 1984 to 1988 and physical examinations of 4,500 men and women ages 45 to 74.

The Honolulu Heart Program, begun in 1965, is collecting epidemiologic and pathologic data on a cohort of 8,006 men of Japanese ancestry who live in Hawaii. Parallel studies of Japanese men in two cities in Japan and of men of Japanese descent in Honolulu are examining differences in CHD and cerebrovascular disease mortality rates between the two groups. The data show a difference in mortality in the two groups of men of similar ethnic origin, which suggests that some environmental factor or factors may play a key role.

A study of weight reduction in Mexican Americans seeks to help Mexican-American families develop a more active approach to maintaining or improving cardiovascular health through changes in their diet and physical activity.

Study Finds Heart Disease Varies Among American Indian Groups

Preliminary data from the Strong Heart Study are available from 2,278 examinations completed to date. These data indicate at least a two-fold difference in CVD among the study groups, with the highest rates in the Dakotas and the lowest rates in Arizona. Cardiovascular disease risk factors also vary among the study centers. The Dakota Indians have the highest rates of smoking and the lowest rates of hypertension; Arizona Indians

have the highest rates of diabetes and obesity, but the lowest rates of smoking and elevated serum cholesterol. Particularly intriguing is the finding that CVD risk factors among these American Indians do not cluster within individuals, as they appear to do in the non-Indian U.S. population. It appears, for instance, that obesity among American Indians does not confer the higher levels of blood pressure or cholesterol that are seen in the white population.

Atherosclerosis Is Developing in Young Black and White Americans

The NHLBI is supporting a unique study, Pathobiologic Determinants of Atherosclerosis in Youth, to follow the natural history of the development of atherosclerosis in the coronary arteries and aortas of young people, ages 15 to 34, who have died in accidents. (In atherosclerosis, the lining of the arteries becomes thickened and irregular with fatty deposits.)

Preliminary data indicate that, for both Black and white males, aortic fatty streaks (the first signs of possible atherosclerosis) can be quite extensive by the second decade of life, and coronary artery fatty streaks and raised fatty plaques may begin to appear by the late twenties. Fibrous plaques (a more advanced stage of atherosclerosis) appear frequently in the abdominal aorta in the third decade of life but are rare in the thoracic aorta.

Fatty streaks are much more extensive in Blacks than in whites. Analyses of data from Black and white males also show highly significant positive associations of high levels of "bad" cholesterol and of cigarette smoking with lesions (tissue injury), and negative correlations of high levels of "good" cholesterol with lesions. Young females appear to develop more fatty streaks than do males and have considerably fewer fibrous plaques than males of comparable age.

Studies Seek to Include More Minorities in Cholesterol Screenings

Public cholesterol screenings have become popular since the advent of portable analyzers and the widely disseminated recommendation of the NHLBI National Cholesterol Education Program that urges adults to know their cholesterol levels.

Minorities are often significantly underrepresented in public cholesterol screenings. Several NHLBI studies are evaluating screening programs designed to overcome this problem by involving all adult segments of the community, especially the harder-to-reach target groups such as men, younger adults, low-income or low-education groups, and minorities.

A screening study currently being conducted by the American Health Foundation in a suburban New York community with approximately equal Black and white populations is evaluating a series of interventions that are designed to increase the

community's awareness of cholesterol, motivate participation in a screening program, and motivate participants identified as having high cholesterol to comply with referral recommendations. Results to date are encouraging. Preliminary analyses indicate that Blacks participated in numbers nearly equal to their proportion in the target population.

Family Support Aids Weight Reduction Among Mexican Americans

An NHLBI-supported demonstration and evaluation project at the Baylor College of Medicine, Houston, Texas, is developing and assessing the effectiveness of a culturally sensitive program to help young Mexican-American families lose weight and reduce their risk of cardiovascular disease by adopting a low-fat diet and a regular exercise program. Young females who received a family-centered version of this program lost more weight and were better able to maintain their weight loss for up to one year than were control subjects who received an individual-centered version of the program.

Blood Pressure in Blacks Does Not Drop at Night

Dr. Gregory Harshfield, an NHLBI grantee at the University of Tennessee in Memphis, has demonstrated racial differences in 24-hour blood pressure patterns between Black and white adolescents. He observed that blood pressure in Blacks is less likely to drop at night and that this trend seems to worsen with age; by adulthood, Blacks have nocturnal blood pressure that remains at daytime levels. NHLBI-supported researchers at the Charles R. Drew University of Medicine and Science in Los Angeles have extended these studies by observing that blood pressure in Blacks born in other parts of the world declines during sleep, as it does among U.S. whites. This phenomenon among U.S. Blacks, called blunted nocturnal decline, imposes additional cardiovascular strain that may explain, in part, the greater prevalence of stroke, left ventricular hypertrophy, and kidney disease in U.S. Blacks as compared with U.S. whites.

Black-White Blood Pressure Differences Found Stable Throughout Childhood

Dr. Joseph Murphy, an NHLBI grantee at the Miriam Hospital, Providence, Rhode Island, found that the significantly greater heart rate and blood pressure reactivity of Black third-graders to a video game stressor was maintained into the fourth and fifth grades and that reactivity was related to subsequent resting blood pressure levels. This study suggests that, among children, Black-white differences in stressor and heart rate reactivity are a stable childhood characteristic and that Blacks may exhibit blood pressure irregularities well before the onset or diagnosis of hypertension.

Obesity, Race, and Gender Are Linked

Two large community-based cardiovascular studies supported by NHLBI have recently reported their findings on obesity in Blacks and whites. The Coronary Artery Risk Development in Young Adults study reported on 18- to 30-year-olds, and the Atherosclerosis Risk in Community study reported on 45- to 64-year-olds. Obesity was found much more often in Black than in white women--30 percent versus 14 percent in the younger group, and 77 percent versus 46 percent in the older group. Black and white men had similar obesity rates.

Studies Explore Identification/Diagnosis Strategies for Children With Asthma

One of the important factors in controlling asthma is continuous access to quality medical care. Many Blacks with asthma do not receive routine medical care and may not be identified as having asthma. Thus, they may not receive care for the disease until an episode becomes severe and emergency treatment is necessary.

NHLBI grantee Dr. Robert Mellins and colleagues at Columbia University, New York City, are working with the New York City Department of Health to increase access to care for minority children with asthma. In a study of 10 child health clinics in the South Bronx, the investigators implemented an intensive education and consultation program for physicians working in the clinics to teach them to identify and diagnose asthma in the children under their care. Following the educational program, the number of children diagnosed as having asthma increased by 87 percent.

Minority Representation in National Marrow Donor Program Improved

Supported by a contract from the NHLBI, the National Marrow Donor Program (NMDP) maintains a registry of nearly 200,000 normal volunteers who have indicated a willingness to donate bone marrow to individuals needing transplants but who lack suitably matched donors. Donors of marrow must be carefully matched to prospective recipients in two successive typing tests. It is important to have a registry with good ethnic balance if the registry is to serve as a resource for all Americans. During the past year, the NMDP has made a concerted effort to improve minority representation among potential marrow donors. As a result, the number of Blacks in the file increased nearly 10-fold, the number of Asian-Americans more than 25-fold; and the number of potential donors of Hispanic descent increased more than 5-fold.

Use of Hydroxyurea Is Effective for Sickle Cell Disease

Hydroxyurea has been shown to increase fetal hemoglobin (a normal hemoglobin everyone has in utero and for a short time

after birth). A number of recent studies have provided convincing evidence that hydroxyurea may offer a potential treatment for sickle cell disease because red blood cells with large amounts of fetal hemoglobin do not "sickle" as readily. Dr. Samuel Charache, of The Johns Hopkins University Hospital, Baltimore, Maryland, and colleagues at five other sites have completed a study to determine the optimum dose and schedule of administration of hydroxyurea to obtain significant levels of fetal hemoglobin in sickle cell patients. Data from 29 patients treated for more than one year showed achievement of fetal hemoglobin levels of 15 percent or higher. Patients reported a significant decrease in pain episodes and improved general well-being.

Research Explores Genetic Therapy for Sickle Cell Disease

The goal of research directed by NHLBI intramural scientist Dr. Arthur Nienhuis is to use gene replacement as therapy for sickle cell disease and other hemoglobin disorders. In the past year, Dr. Nienhuis using nonhuman primates, has been able to introduce a globin gene into the bone marrow stem cells that manufacture blood cells and obtain expression of the gene. However, only 1 percent of the cells in monkeys undergoing the gene transfer procedure contained the inserted gene. Present efforts seek improved transfer efficiency by concentrating on the mouse model.

NHLBI Provides Assistance to Minority Students and Schools

Over the years, NHLBI has promoted minority involvement in biomedical research by encouraging minorities at all academic levels to participate in the Institute's research training and career development programs. These programs include the Minority Access to Research Careers (MARC) Program, the Minority Biomedical Research Support (MBRS) Program, the Minority Institutional Research Training (MIRT) Program, the Minority School Faculty Development Award, and the Initiatives for Underrepresented Minorities in Biomedical Research Program (supplemental awards to existing and research projects). In addition, NHLBI and several other institutes offer MARC honors students a 10-week summer research experience in NIH intramural laboratories. During the summer of 1990, nine students (six Blacks, one Hispanic, and two American Indians) from eight different minority institutions participated in the NHLBI program.

National Cancer Institute

Cancer surveillance data emphasize that minority groups have disproportionately high rates of cancer mortality and special problems in terms of access to state-of-the-art cancer prevention, early detection, and treatment. The National Cancer Institute (NCI) has made reduction of cancer mortality in these groups a high priority. NCI also has intensified efforts to recruit and train minorities in the sciences and cancer-related research.

Minority Health Professionals Are Recruited

NCI's Comprehensive Minority Biomedical Program (CMBP) supported 20 new minority investigators during 1990.

In July 1990, NCI held its first Summer Science Enrichment Program, a six-week program designed to stimulate interest in science careers among minority students and students from poor and underserved areas such as Appalachia. A total of 107 high school sophomores participated in the program held at Hood College in Frederick, Maryland.

The Developmental Studies Research Program recruits Hispanic, Asian, and Black researchers to conduct cancer research within their respective minority groups.

Outreach Efforts Are Increased

NCI has a number of programs that seek to increase cancer prevention awareness and access to state-of-the-art cancer treatment in underserved populations. The National Black Leadership Initiative on Cancer is the Institute's formal outreach initiative to enlist concerned and active Black leaders throughout the nation to organize cancer prevention programs.

NCI is assisting the District of Columbia Health Department and other groups to address the high rates of cancer mortality in the District. The strategies developed for the District will be applied to Black communities throughout the nation.

As part of an effort to increase minority participation in clinical trials, NCI's minority-based Community Clinical Oncology Program made awards to 12 institutions with greater than 50 percent of their patients from minority populations.

Requirements for cancer centers to be granted comprehensive status were modified this year to emphasize outreach to special populations with disproportionately high cancer rates, including minorities. (Comprehensive centers do the entire range of activities from basic and clinical research to the kinds of outreach that are related to prevention and control of cancer in the communities they serve.)

National Institute of Dental Research

The National Institute of Dental Research (NIDR) supports research targeted to minority oral health problems and encourages minorities to pursue dental research careers.

New Findings May Lead to New Treatments for Oral Cancer

Oral cancer is more prevalent among Black men than among any other population group. Further, the 5-year survival rate associated with this disease is worse among minorities than among whites. NIDR grantee Dr. Edward J. Shillitoe at the University of Texas Health Science Center in Houston identified a new protein in herpes simplex virus that is tentatively believed to be involved in the development of oral cancer. He and his colleagues found antibodies against the protein in patients with this disease and, using cells from patients, have begun experiments to develop new methods of therapy.

Alcohol Enhances the Oral Effects of Smokeless Tobacco

Dr. Christopher A. Squier, an NIDR grantee, and his colleagues at the University of Iowa in Iowa City showed that alcohol acts as a solvent, enhancing penetration in the oral mucosa of cancer-causing agents found in smokeless tobacco. Their basic research findings, which support other similar findings, are particularly relevant to Native Americans, who use far greater amounts of smokeless tobacco than other groups.

Patterns of Dental Disease Differ Between Blacks and Whites

Results from a long-term epidemiological study of an older population show that Blacks age 65 or older, compared with whites of similar age, have more severe gum disease, require restorative treatment and extractions more often, and utilize dental services less. This NIDR-supported study is being conducted by Dr. James D. Beck and colleagues at the University of North Carolina at Chapel Hill.

Council Subcommittee Established for Minority Activities

Recognizing the importance of enhancing minority oral health and improving opportunities for minority researchers, the National Advisory Dental Research Council, at the request of the Director, NIDR, established a subcommittee on minority activities to promote initiatives in this area. NIDR already participates in the NIH Minority Research Supplement Award and minority student training programs.

National Institute of Diabetes and Digestive and Kidney Diseases

Among the research supported by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) are studies focusing on various diseases that disproportionately affect minority populations.

Genetic Link Suggested for Gallstone Disease in Hispanics

NIDDK grantee Dr. William J. Schull and coworkers at the University of Texas Health Sciences Center in Houston are evaluating the causes and frequency of gallstones among American Hispanics in the Southwest. From 1,000 randomly selected Mexican American residents of Starr County, Texas, the researchers selected 150 individuals with gallstone disease and 150 controls who were free of gallstones and matched for age, sex, and locality of residence. Genetic risk of gallstone disease was examined by assessing its frequency in relatives of each group. Preliminary data indicate that relatives of a person with gallstone disease have a 1.6-fold increased risk of having gallstones compared with relatives of gallstone-free controls.

Renal Diseases Found Higher Among Blacks

The U.S. Renal Data System (USRDS), funded by NIDDK under contract with the Urban Institute, presented in its first annual report a detailed statistical picture of kidney disease in the United States. The reports show that kidney failure is more common among Blacks than among whites. Blacks, who comprise 12.3 percent of the U.S. population, account for 28 percent of end-stage renal disease (ESRD) patients. The most striking difference is among Blacks 25 to 44 years of age, who have more than 20 times the rate of renal failure as whites. USRDS data also showed that although Blacks with ESRD fare better on dialysis and have a 15 percent lower death rate than whites, Blacks have greater Kidney transplant rejection rates.

NIDDK Encourages Training Grants for Minorities

NIDDK has made a strong commitment to promoting both biomedical research in minority institutions and the participation of minorities in biomedical research. NIDDK encourages active grantees to apply for administrative supplements for the support of underrepresented minority scientists and students. Also, in an effort to increase the number of physicians and basic scientists from underrepresented minorities who receive research training through Institutional Training Grants, NIDDK provides training slots to minorities to receive research training under the guidance of nationally recognized researchers.

National Institute of Neurological Disorders and Stroke

The National Institute of Neurological Disorders and Stroke (NINDS) supports and conducts research and research training on several diseases and conditions that have a disproportionate impact on minority populations. These include:

Low birth weight. Brain hemorrhage affects nearly half of all very-low-birth-weight infants, many of whom are minority children. Based on positive results in her earlier studies of newborn beagles, NINDS grantee Dr. Laura R. Ment at Yale University in New Haven, Connecticut, is now testing the efficacy and safety of the drug indomethacin in preventing brain bleeding in low-birth-weight infants.

In another study, NINDS grantee Dr. Edward H. Perry and colleagues at the University of Tennessee in Memphis demonstrated that fewer intensive care interventions for low-birth-weight babies may decrease episodic blood pressure increases, with the result that brain bleeding is less likely to occur.

Epilepsy. NINDS grantee Dr. George E. Locke at Charles R. Drew University of Medicine and Science in Los Angeles, California, is analyzing data from a study just completed that was designed to determine the frequency of, and factors associated with, the development of epilepsy and other seizure disorders among people in underprivileged urban communities.

NINDS-supported research on stroke, diabetic neuropathy, and AIDS, all of which have a major impact on minority health, is described in separate reports.

NINDS Promotes Training and Career Development for Minorities

NINDS participates in the NIH Initiatives for Underrepresented Minorities in Biomedical Research and the Minority High School Student Research Apprenticeship programs. In addition, NINDS provides short-term training in basic and clinical neurological research for minorities through its Summer Program in the Neurosciences. In the summer of 1990, the summer program included 27 minority students--43 percent of the total. Several minority students who participated in previous summer programs returned to NINDS as research fellows after completing their medical specializations.

The pool of minority scientists engaged in research on the brain and nervous system is extremely small. Following meetings with representatives of the Association of Minority Health Professions Schools, NINDS inaugurated a program enabling students and science faculty at historically Black colleges and universities to conduct investigations at NINDS grantee research institutions located in their area.

National Institute of Allergy and Infectious Diseases

The National Institute of Allergy and Infectious Diseases (NIAID) strives to improve the health status of U.S. minorities through its research programs.

AIDS Among Minorities Is a Major Research Focus

Epidemiological studies reveal that minorities comprise 45 percent of the Nation's AIDS cases, highlighting the critical need to augment minority participation--as patients, health care providers, and researchers--in AIDS clinical trials. In view of this deficiency, supplemental funds were awarded to 16 NIAID-supported AIDS Clinical Trials Units to expand the enrollment of Blacks and Hispanics. Cooperative agreement awards were made to minority institutions in Washington, D.C., Hawaii, and Puerto Rico to enable them to evaluate promising therapies for use against HIV infection and opportunistic infections.

Dr. Rudolph E. Jackson of Morehouse University School of Medicine in Atlanta, Georgia, was awarded a grant for an AIDS Consortium Center in which seven Black health professions schools that constitute the Association of Minority Health Professions Schools are participating. The consortium will coordinate intensive prevention and research activities aimed at reducing the incidence, morbidity, and mortality of HIV infection among minorities. The consortium will also address epidemiology and prevention, drug development, clinical trials, and animal models.

The current sexually transmitted disease (STD) epidemic in the United States disproportionately affects the health of minorities. NIAID will play a major role in a new interagency group formed to expedite development of more efficient ways to diagnose STDs tailored to the needs of U.S. inner cities and developing countries that lack adequate resources in this area. The group includes representatives of the Centers for Disease Control, the World Health Organization, and the U.S. Agency for International Development.

Of particular concern to NIAID are the spiraling rates of asthma-related deaths and hospitalizations among young Blacks and other minority groups. NIAID co-sponsored, with Howard University in Washington, D.C., a community outreach activity for children with asthma. Five hundred children and their parents and teachers participated in activities designed to raise awareness about asthma and the ways in which it can be successfully managed.

Disseminating information to health care workers practicing in minority communities continues to be an NIAID priority. A number of NIAID publications on such topics as asthma, AIDS-related opportunistic infections, AIDS clinical trials, and AZT therapy have been translated into Spanish and distributed.

National Institute of General Medical Sciences

The National Institute of General Medical Sciences (NIGMS) is dedicated to increasing the number of scientists who are members of minority groups that are presently underrepresented in biomedical research. Individuals from these groups constitute a vast, largely untapped source of the scientists and engineers needed to help the United States maintain its scientific and technological competitiveness. Toward this end, NIGMS sponsors special research and research training programs for students and faculty members at minority institutions and actively participates in an NIH-wide effort to promote the involvement of minority scientists in ongoing research.

MBRS Program Moves to NIGMS

At the start of FY 1990, NIGMS assumed administration of the Minority Biomedical Research Support (MBRS) Program from the NIH Division of Research Resources (now the National Center for Research Resources). The MBRS Program provides research grants to colleges, universities, and health professional schools with substantial minority enrollments, as well as to tribally controlled institutions on Indian reservations. These grants support research by faculty members, provide opportunities for students to work as part of a research team, and strengthen the institutions' biomedical research capabilities.

During its 18 years of operation, the MBRS Program has contributed to the development of research programs at over 90 minority institutions. Many of these had previously conducted little or no research. In addition, many of the approximately 16,000 students who have participated in MBRS-supported research projects have become or are now working to become biomedical researchers.

The MBRS Program provides support through two major grant mechanisms. One, the MBRS Traditional Program, primarily supports faculty research projects but also places emphasis on promoting the involvement of undergraduate and graduate students. The MBRS Program for Undergraduate Colleges supports enrichment activities, pilot research projects, and regular research projects at undergraduate institutions. Enrichment activities, which are a required component of this type of grant, include workshops, attendance at scientific meetings, and summer research experiences for faculty and students at off-campus laboratories.

An MBRS grantee, Dr. Thomas Onak at California State University, Los Angeles, received the 1990 American Chemical Society Award for Research at an Undergraduate Institution. This award, which is the highest research honor made to a chemist at a non-Ph.D.-granting American institution, recognizes Dr. Onak's pioneering contributions in the field of inorganic chemistry. It is the first time that this award has been given to a faculty member at a predominantly minority institution.

MARC Program Continues To Train New Scientists

The NIGMS Minority Access to Research Careers (MARC) Program, which began in 1972, awards research training grants to increase the number and capabilities of minority biomedical research scientists and to strengthen science curricula and research opportunities at minority institutions.

The centerpiece of the MARC Program is its Honors Undergraduate Research Training component. It helps minority institutions develop strong undergraduate science curricula, stimulate an interest in biomedical research among undergraduate students, and increase the number of well-prepared minority students who can compete successfully for entry into graduate programs leading to the Ph.D. degree in the biomedical sciences. The honors undergraduate program has supported approximately 1,500 students since its inception in 1977. The program currently supports students at 60 minority institutions. It is notable that at these institutions, the number of students earning degrees in the biological sciences has increased, while the percentage of all students nationwide (minority and non-minority) earning biological science degrees has decreased. To date, approximately three-quarters of the graduates of the honors undergraduate program have gone on to either graduate or professional schools.

An important element of the honors undergraduate program is the summer research experience outside the home institution. Juan Carlos Arguello and Eddie Mendez, NIGMS-supported MARC students at Barry University in Miami, Florida, spent the summer of 1989 working with Dr. Katharine Atkinson at the University of California, Riverside. Dr. Atkinson is using molecular genetic techniques to analyze the resistance of certain bacteria to various antibiotics. Understanding the mechanisms of this resistance could help scientists find ways to foil it, and also may suggest approaches to developing new, more powerful antibiotics. The Barry students' summer project went so well that Dr. Atkinson invited them to return to Riverside during the 1989-1990 winter break to continue their research.

Graduates of the honors undergraduate program who want to pursue a Ph.D. or M.D.-Ph.D. degree are eligible for a MARC predoctoral fellowship. NIGMS is proud that some of these students also are able to secure predoctoral funding on their own, often from graduate schools that are anxious to recruit them.

The MARC Program also provides opportunities for advanced research training to selected faculty members of minority institutions. This training may lead to a Ph.D. degree or involve postdoctoral research. When the training period is completed, fellows are expected to return to their sponsoring schools to teach and conduct research. Since 1972, 225 individuals have received support under this program. Of those

who have completed their training, approximately 90 percent returned either to their original home institution or to another minority institution.

NIGMS Contributes to the NIH Minority Initiative

In the first 17 months of the NIH program to increase the number of minority individuals who participate in ongoing, grant-supported research projects, NIGMS received 102 applications from current grantees requesting supplements for this purpose. To date, 79 awards have been made (64 of them in FY 1990), primarily to graduate and undergraduate students.

National Institute for Child Health and Human Development

The mortality rate of Black infants is twice that of infants born to white women. The National Institute for Child Health and Human Development (NICHD) supports a broad range of research activities focused on decreasing the infant mortality rate. Findings from this effort will benefit infants of all races, but some projects are targeted to minority groups.

Predictive Marker for Preeclampsia Is Found

Preeclampsia, or elevated blood pressure during pregnancy, affects at least 5 to 6 percent of women pregnant for the first time, but up to 20 percent of indigent inner-city pregnant women suffer from this condition. Preeclampsia causes substantial increases in both maternal and fetal morbidity and mortality. Early diagnosis of the condition is essential so that prompt medical treatment can be given.

A group of investigators headed by NICHD grantee Dr. James B. Sowers at Wayne State University in Detroit, Michigan, studied 45 first-time-pregnant young Black women throughout the course of their pregnancies. Fourteen of them developed preeclampsia by the last three months of their pregnancy. Dr. Sowers and his colleagues analyzed their blood and measured fluctuations in blood pressure and levels of intracellular calcium. The results point to a possible early biochemical marker to predict the subsequent development of preeclampsia in otherwise healthy women. Women identified as being at risk for preeclampsia can be monitored closely during pregnancy, improving the likelihood of a successful pregnancy outcome for both mother and child.

Mouse Model for Sickle Cell Anemia Should Aid Research

Although the genetic defect that causes sickle cell anemia was discovered more than 30 years ago, there are few treatments for this debilitating disease, in part because scientists have lacked an animal model in which to test treatments. Now, NICHD-supported investigators headed by Dr. Ralph Brinster at the University of Pennsylvania in Philadelphia and colleagues at the Universities of Alabama in Birmingham and Washington in Seattle have developed a model by implanting the human sickle cell gene into mice. This model may prove invaluable for testing new drugs and gene therapies for this disease and may lead to better ways to combat the organ damage associated with sickle cell anemia.

National Eye Institute

Data from small studies have suggested that blindness and visual impairment are more prevalent among Blacks than among whites. To obtain more definitive information on racial variations in vision loss that might be useful in developing effective community-based interventions, investigators at The Johns Hopkins Medical Institutions in Baltimore, Maryland, -- supported by the National Eye Institute (NEI) -- conducted the Baltimore Eye Survey. The scientists surveyed more than 5,000 residents ages 40 and older who live in racially mixed East Baltimore neighborhoods. Of the participants, 2,395 were Black and 2,319 were white.

The investigators looked at two levels of vision loss: legal blindness and visual impairment that would significantly limit a person's ability to function in society. Nearly twice as many Blacks as whites were found to be legally blind or visually impaired. The prevalence for both levels of vision loss rose rapidly with age in both racial groups, but the increase was much higher for the Black population and started at an earlier age.

Of the Blacks surveyed, 1.55 percent were found to be legally blind, compared with 0.93 percent of the whites, while 3.35 percent of the Blacks and 2.68 percent of the whites had a visual impairment that could not be corrected with glasses. The prevalence of blindness did not differ according to sex in either group.

The rate of visual impairment increased rapidly after age 60 for both races. In Blacks, the prevalence of visual impairment was 3.43 percent at age 60, rising to 18 percent by age 80 and older. In whites, the rate of visual impairment was 1.09 percent at age 60, rising to 14.56 percent by age 80 and older. However, by age 80, blindness and impairment rates were almost equal for the two races.

The scientists discovered, with some surprise, that a new pair of glasses considerably improved the vision of most of those in both races who had impaired vision. When fitted with the best eyeglass prescription, 54 percent could read an additional one or more lines on the eye chart, and 7.5 percent could read another three or more lines. The researchers do not know why such a large number of people, most of whom claimed that they had regular eye examinations, were wearing glasses with an incorrect prescription.

National Institute of Environmental Health Sciences

The National Institute of Environmental Health Sciences (NIEHS) conducts research on environmental agents and chemicals that may adversely affect human health. Socio-economic factors may place minority or ethnic populations at disproportionately high risk of exposure.

NIEHS Studies Effects of Lead Toxicity

Lead is ubiquitous in our environment and can cause serious health effects, including central nervous system damage. Lead exposure comes from many sources, such as flaking lead-based paint, leaded gasoline exhaust, and the roadside dusts contaminated by auto exhaust. Deteriorating inner-city housing has high numbers of minority residents, who are more likely to be exposed to high levels of lead than the general population.

NIEHS grantees in many reports have demonstrated that lead exposure in children adversely affects neurobehavioral function. Dr. Herbert Needleman at the University of Pittsburgh in Pennsylvania has monitored a group of children for 14 years and has found that elevated lead levels in infants seem to be associated with later-occurring reading disabilities, delinquent activities, and reduced high school graduation rates. NIEHS grantees Dr. H. Vasken Aposhian at the University of Arizona in Tucson and Dr. John Rosen at Montefiore Medical Center in New York City are investigating treatment procedures for reducing the lead content of the blood once exposure has occurred. NIEHS intramural scientists Drs. Michael Dieter and Kathryn Mahaffey are directing basic research studies aimed at understanding the mechanism of lead toxicity in the body. All of these studies are important to understand and possibly prevent the long-term effects of lead exposure.

Minority Supplement Grants Are Funded by NIEHS

NIEHS has aggressively implemented the NIH initiative to increase minority participation in biomedical research by awarding 10 minority supplement grants in FY 1990. These grants will increase the number of minority scientists in environmental health research careers, offsetting the present lack of minorities in this important area. These supplements are provided for minority students and investigators who participate in previously approved grants; they are given an opportunity to interact with scientists on the parent grant, to contribute scientifically to research projects approved in the parent grant, and to enhance their own research skills.

National Institute on Aging

The National Institute on Aging (NIA) supports biomedical, social, and behavioral research and training related to aging processes, diseases common in old age, family care for dependent older people, and other special needs of the older population. The Institute is especially interested in research to improve the health and longevity of minority populations.

Ethnic Differences in the Use of Health Care Is Studied

Researchers interested in the use of health services by older Americans have long recognized the marked differences in individual characteristics that exists among older persons as they age, and the wide variation among older people using health services. Scientists have recently begun to look at how ethnic variations influence physician visits and use of services.

NIA grantee Dr. Frederic D. Wolinsky and his colleagues at Texas A&M University in College Station examined data from the 1976-1984 Health Interview Survey conducted by the National Center for Health Statistics. They looked at health care use -- physician visits and hospitalizations -- reported by over 4,000 individuals. They found that, overall, minority older people are more likely to visit a doctor because of a specific need, while their nonminority counterparts appear to make more discretionary visits to the doctor such as for checkups. The investigators concluded that older minority individuals seek care only when there is an immediate need; poorer access to health services influences this pattern.

Within the minority older population, there also are indications of heterogeneity in individual characteristics that are important in explaining or predicting patterns of health care utilization. Major findings related to diversity of health care use among several minority subpopulations include: (1) Among the Hispanic subpopulations, Puerto Ricans and Mexican Americans face greater socioeconomic disadvantages than their Cuban American counterparts. A disproportionately larger number of the latter are immigrants with professional backgrounds, a fact reflected in health care use among older Cuban Americans that differs from that in other Hispanic subpopulations. (2) Older Blacks visit the doctor more often than other groups, possibly because they have more serious and limiting health problems. (3) Puerto Ricans and Mexican Americans are more likely to visit a doctor when their physical activity is limited, perhaps because they are more likely to have occupations that require physical activity. (4) Puerto Ricans and Blacks appear on average to have longer hospital stays, especially when compared with whites. This disparity may be the result of the severity of the condition which necessitates hospital admission.

National Institute of Arthritis and
Musculoskeletal and Skin Diseases

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) has over 60 grants, covering all three of its major research fields, that pertain to minority populations.

NIAMS is cofunding with NIGMS research at minority institutions through the MBRS and MARC programs. The Institute also developed two joint programs with NIDDK--the Minority Investigator Research Enhancement Award and the Minority Travel Award Program.

Impact of Certain Rheumatic and Musculoskeletal Diseases on
Minority Populations Studied

Systemic lupus erythematosus (SLE), an autoimmune condition, particularly affects Black women of child-bearing age. NIAMS grantee Dr. John D. Reveille at the University of Texas Health Science Center in Houston and colleagues at the University of Alabama in Birmingham examined survival, by life-table analysis, in an approximately evenly divided group of 389 U.S. Blacks and whites. They found that both Black race and increasing age at the onset of SLE independently worsened the likelihood of survival.

Dr. John A. Klippel, an intramural scientists at NIAMS, and his colleagues completed a 16-year trial that found that prednisone, when combined with cyclophosphamide, is effective in preventing kidney scarring, and therefore kidney damage, in patients with severe lupus nephritis. Positive results became evident after seven years of treatment.

NIAMS grantee Dr. Chella S. David at the Mayo Clinic in Rochester, Minnesota, genetically manipulated mice so that they carried in their blood the human genetic marker HLA-B27, which is found more often in Native Americans than in other populations and is associated with ankylosing spondylitis, a rheumatic disease affecting the spine. The altered mice were more likely than normal mice to die following bacterial infection, thereby providing a mechanism to investigate the role of the immune system in ankylosing spondylitis. Although HLA-B27 has been linked to ankylosing spondylitis for many years, this study provides the first indication that HLA-B27 is directly involved in the disease.

NIAMS grantee Dr. Richard L. Bauer at the University of Texas Health Science Center in San Antonio used 1980 census data to calculate the ethnic-group-specific incidence of hip fractures and found that hip fractures were more common among non-Hispanic white women (139 per 100,000) than among Mexican American women (67 per 100,000) or Black women (55 per 100,000).

National Institute on Deafness and Other Communication Disorders

The National Institute on Deafness and Other Communication Disorders (NIDCD) conducts and supports research and training on normal mechanisms of communication as well as disorders of hearing and other communication processes, including diseases affecting hearing, balance, smell, taste, voice, speech, and language.

NIDCD participates in the NIH Minority Biomedical Research Support Program and Initiatives for Underrepresented Minorities in Biomedical Research Program. Besides supporting Blacks, Hispanics, Native Americans, and Asian/Pacific Islanders, NIDCD supports deaf scientists and students as a minority group. The Institute has taken an active role in recruiting applicants for these programs and in generating interest among them. The growth and potential of these programs in NIDCD is indicated in the following data:

NIDCD Minority Supplements		
	FY 1989	FY 1990
Number submitted	2	22
Number awarded	1	18
Areas of awarded supplements:		
Hearing/Vestibular	1	5
Voice/Speech/Language	0	6
Taste/Smell	0	7

Examples of NIDCD initiatives that are expected to benefit minority populations include:

Noise and Hearing Loss. Noise exposure represents the most common preventable cause of hearing loss. NIDCD has targeted this area of research and is developing a major public education campaign on it. Minorities may be at particular risk for noise-induced hearing loss in the workplace because they are frequently the operators of equipment in both manual-labor and heavy-industry environments.

Small Grants. The NIDCD Small Grants Program provides opportunities for scientists to participate in communication sciences research without competing for funding through traditional mechanisms. It is expected to increase the participation of minority investigators in NIDCD research areas.

Population-based Studies. Sound epidemiologic data on communication disorders is a critical need in all areas of NIDCD research, particularly in minority sections of the population. NIDCD is developing data expected to be useful in identifying the impacts of communication disorders on minority populations which will enable the Institute to develop effective strategies for addressing these issues.

National Center for Research Resources

Historically, minority educational institutions have played a major role in training the medical professionals who provide health care to minority communities. Support from the Research Centers in Minority Institutions (RCMI) Program of the National Center for Research Resources (NCRR) strengthens the research infrastructure of these schools, permitting them to recruit new faculty members, renovate laboratories, install state-of-the-art scientific equipment, and expand their capacity to do biochemical and behavioral research.

In 1990, the RCMI program made awards to 17 institutions, including three colleges of pharmacy, seven medical schools, six graduate schools, and one school of veterinary medicine. Total funding was about \$19 million, including nearly \$1.3 million provided by NIAID for development of a research infrastructure for AIDS and AIDS-related research.

In AIDS patients, cytomegalovirus (CMV) can cause life-threatening disease and blindness. To study how the human immunodeficiency virus (HIV) infects the tissues of the eye and how this virus may influence cytomegalovirus (CMV) infection, NCRR-supported RCMI grantees at the Morehouse School of Medicine in Atlanta, Georgia, have developed techniques for growing retinal pigment cells taken from the eye. Grantee Dr. Kamla Dutt found that the cultures support active growth of HIV after the virus is artificially introduced into the cells by a process called transfection. Dr. Dutt and her colleagues have altered several retinal pigment cell lines genetically to increase their longevity, thereby making research on HIV infection more efficient. Use of these culturing techniques may help clarify the respective roles of CMV and HIV in the blindness that often accompanies AIDS.

National Center for Nursing Research

The National Center for Nursing Research (NCNR) continues to promote opportunities for minority participation in nursing research. The Center funds administrative supplements to recruit and train minority nurses at institutions holding National Research Service awards, research grants to support minority individuals, and center grants to recruit and train minorities in research and promote linkages with minority nursing faculty.

NCNR also supports research to improve the methods nurses and other health professionals use to prevent and provide care for health problems that are especially prevalent among minority populations. Included are studies to better understand the unique cultural factors involved in maintaining or improving health in minority groups and to improve minority access to health care.

Benefits of Nurse Home Visits to Pregnant Women and Their Babies Analyzed

A third of all pregnant women lack sufficient prenatal care, and this percentage is higher among Blacks. In 1988, 13 percent of the babies born to Black women had low birth weights.

NCNR grantee Dr. David L. Olds and his colleagues at the University of Rochester Medical Center in New York, are testing the extent to which prenatal and postpartum nurse home visits enhance the health and well-being of socially disadvantaged women and their first-born children. The study population is 90 percent Black; 75 percent are teenagers, and 80 percent have incomes below Federal poverty guideline levels.

Over 1,400 women living in Memphis, Tennessee, will be enrolled in the study. Half of the women will receive nurse visits during pregnancy and infancy, transportation for prenatal care, and sensory and developmental screening for the infants. One-third of these families will continue to receive visits through the second year of the baby's life. They will be compared with women who receive only transportation for prenatal care plus infant sensory and developmental screening. In the home visitation group, Dr. Olds and his research team will look for improvements in prenatal health habits, infant caregiving, and mothers' educational and occupational achievements. They also will look for fewer unwanted additional pregnancies and reduced reliance on welfare.

The investigators will compare the rates of prematurity and low birth weight, growth and nutritional problems, accidents, acute infectious illnesses, cognitive delays, behavioral problems, and abuse or neglect among the children.

National Library of Medicine

The National Library of Medicine (NLM) believes that improved access by health professionals to information in MEDLINE and NLM's other computerized databases will result in higher quality health care for the nation's citizens. Responding to a 1988 directive from Congress, NLM initiated projects to put access to such information in the hands of every health professional, especially those located in isolated rural areas, many of whom serve substantial minority populations..

Among FY 1990 projects were the following: (1) an award to the University of Texas is testing the "circuit librarian" concept as a means of bringing improved services to a rural area with a large Hispanic population; (2) thirty contracts were awarded to medical libraries in 22 states to reach out to "unaffiliated" health practitioners; the results are expected to improve health care for Native Americans in states like Arizona and Alaska, Blacks for example, in Brooklyn, New York, and in rural areas of South Carolina, and other minorities; (3) a contract to Meharry Medical College in Nashville, Tennessee, has made possible a project to use the latest technologies to help practitioners serving economically depressed Black populations in Tennessee.

OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH**Office of Minority Health****Minority Health**

The Secretary's Task Force on Black and Minority Health was established in 1984 to explore and document the historical disparity which exists between the health status of minority Americans and the non-minority population. The findings of the Task Force and its resulting report have given the Department a framework within which to address the complex problems underlying the disparities.

The Task Force Report documented over 60,000 excess deaths each year among Asian/Pacific Islanders, Blacks, Hispanics and Native Americans. Excess deaths are defined as deaths that would not have occurred if the death rate of minorities were the same as the death rate for the non-minority population. The Task Force concluded that 80% of the excess deaths were due to six causes: cancer, cardiovascular disease and stroke, chemical dependency, diabetes, infant mortality and violence. Since the issuance of the report, AIDS has been identified as the seventh contributor to excess deaths.

The Office of Minority Health was created to be the focal point for the implementation and monitoring of the Task Force recommendations and for the formulation and development of policies affecting minority health. Public Law 101-527, the "Disadvantaged Minority Health Improvement Act of 1990" authorized the office in statute to continue its efforts to improve the health of individuals from disadvantaged backgrounds, including minorities and to continue to implement the recommendations of the Task Force Report.

To carry out its mandate, the Office works closely with the Public Health Service agencies and other components of the Department in a catalytic, coordinative, advocacy and policy development role to: (1) assure that minority health care needs are a priority in Departmental resource allocation decisions, (2) establish short-term and long-range objectives for Departmental health policies addressing minority populations, (3) develop appropriate monitoring systems to ensure that these objectives are met, (4) encourage cooperative and collaborative efforts among PHS agencies to address specific minority health needs, and (5) encourage and initiate the development and use of innovative approaches for decreasing the gap in health status between minority and non-minority populations.

The need for greater Departmental coordination and elevation of the problems of minority health to a level of strategic importance led to the formation of the PHS - Minority Health

Strategic Planning and Coordinating Process. This was established as a mechanism to define the short and long-range goals and objectives in the various disease areas which contribute to excess deaths among minorities as well three additional health problem areas with crosscutting implications for minority health: financing of and access to health care, health professions and data. Accomplishments to date include: the establishment of nine Health Issues Working Groups which have completed a systematic assessment of current PHS agency activities and plans which address minority health issues, development of a minority health strategic plan which contains long and short-range goals and objectives to be implemented by the public and private sector, and a soon-to-be completed computerized database of PHS programs/projects which have substantial impact on minority populations.

A second example of the Office's coordinative functions is its lead role in one of the Secretary's program directions. The OMH has been assigned lead role for program direction number nine: "Improve the health status of minority and low-income persons, and reduce disparities in the incidence of premature death, chronic diseases, and injuries."

The Office has also been assigned the lead for the Secretary's initiative to respond to the minority male crisis. In a very short period of time, the Office developed and implemented a Department-wide grant program to support the health and human service needs of minority males across the country. Funding for this grant program was obtained from PHS agencies and other components of the Department. In FY 1990, the Office awarded approximately \$2.4 million in grants to empower communities to address the wide range of health and human service needs of at-risk minority males. Grants to develop community coalitions were awarded to 25 organizations in 16 states, and conference grants were awarded to 58 organizations in 29 states and the District of Columbia.

Among other ongoing program efforts, the Minority Community Health Coalition Grant Program provides three-year demonstration funding to support community-based organizations which will target intervention activities to specific minority groups to promote health, reduce risk factors for health problems, including human service needs. These projects are based on the concept that greater force for change can be achieved by expanding the base of community awareness, support and involvement. Projects selected for funding have been designed with unique and innovative approaches for the reduction of risk factors for specific health problems in their specific communities. Some projects which have been funded include the Continuum Alliance for Healthy Mothers and Children which will address Black infant mortality in Fulton and Terrell counties of Georgia; Community Partnership for the Prevention of Alcohol and Drug Problems Among Latino Youth in Perth Amboy, New Jersey; San Diego Samoan Community Exercise for Better Health Project; and the Fort Defiance Area Native American AIDS Education Project.

The second grant program administered by the Office is the AIDS Education/Prevention Grant Program. This activity as well as other efforts in this health priority area are discussed in the separate program submission for AIDS.

Another accomplishment of the Office of Minority Health is the establishment and operation of the Office of Minority Health Resource Center (OMHRC) which maintains information on minority health-related resources available at the Federal, state and local levels. Components of the OMHRC include a computerized database of minority health-related materials, organizations, and programs; a nationwide toll-free information line through which OMHRC bilingual (Spanish-English) information specialists respond to inquiries or refer inquiries regarding the seven minority health priority areas to the appropriate organizations and locate relevant materials; and a OMHRC Resource Persons Network which links professionals knowledgeable and active in minority health with minority community-based organizations and voluntary groups who want to become more active in health but lack the technical knowledge to do so.

The Office of Minority Health also sponsors or supports several workshops and conferences throughout each year. Some examples of these are a national conference on AIDS and HIV Infection in Racial and Ethnic Populations conducted by the OMH in 1989, seven regional follow-up conferences on AIDS in minority populations to be completed in FY 1991, a National Conference on Barriers to Health Care Financing in Minority Populations, and the District of Columbia Violence Intervention Conference: A Matter of Life or Death, the 1990 Annual Conference of the National Council of La Raza, the 1990 national meeting of the National Medical Association, and the 1990 meeting of the Asian American Health Forum entitled: "Dispelling the Myth of a Healthy Minority."

There has, in addition, been a continuing demand for technical assistance workshops on grants writing as well as on program specific requirements of the Minority Community Health Coalition Grant Program and the AIDS Prevention/Education Grant Program. The Office also actively supports the Historically Black Colleges and Universities (HBCU) Initiative. Early in FY 1990 the Office conducted two technical assistance workshops specifically for faculty members of HBCUs to improve their ability to compete for Federal financial assistance. The Office is currently exploring avenues to conduct similar activities with the Hispanic Association of Colleges and Universities (HACU).

PEDIATRIC ACQUIRED IMMUNODEFICIENCY SYNDROME

	Obligations -----				
PUBLIC HEALTH SERVICE:	1988 Actual	1989 Actual	1990 Actual	1991 Estimate	1992 Estimate
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National Institutes of Health:					
National Institute of Allergy and Infectious Diseases.....	\$17,083,000	\$22,769,000	\$30,937,000	\$41,853,000	\$55,339,000
National Cancer Institute.....	2,685,000	3,940,000	9,091,000	11,906,000	12,976,000
National Heart, Lung, and Blood Institute.....	---	1,630,000	4,926,000	4,938,000	6,509,000
National Institute of Dental Research	---	---	112,000	125,000	133,000
National Institute of Diabetes and Digestive and Kidney Diseases	---	---	401,000	415,000	435,000
National Institute of Neurological Disorders and Stroke.....	943,000	1,131,000	2,698,000	2,752,000	2,918,000
National Institute of Child Health and Human Development....	14,047,000	18,045,000	24,361,000	26,300,000	28,800,000
National Institute on Aging.....	---	---	---	44,000	48,000
National Center for Research Resources.....	2,350,000	7,561,000	4,497,000	4,449,000	4,270,000

National Center for Nursing Research.....	162,000	160,000	458,000	300,000	350,000
Total, National Institutes of Health.....	37,270,000	55,236,000	77,481,000	93,082,000	111,778,000
	=====	=====	=====	=====	=====
Centers for Disease Control..	19,000,000	24,685,000	27,709,000	42,237,000	42,237,000
Alcohol, Drug Abuse, and Mental Health Administration...	7,246,000	8,250,000	12,414,000	13,960,000	15,215,000
Health Resources and Services Administration...	4,787,000	7,806,000	14,803,000	19,518,000	19,518,000
Agency for Health Care Policy and Research.....	---	---	263,000	1,011,000	955,000
Total, Public Health Service...	68,303,000	95,977,000	132,670,000	169,808,000	189,703,000
	=====	=====	=====	=====	=====

NATIONAL INSTITUTES OF HEALTH

PEDIATRIC AIDS

Among some groups of children and young people in the United States, acquired immunodeficiency syndrome (AIDS) has become a leading cause of death. As of September 1990, more than 2,600 children younger than 13 years of age had been reported to have AIDS; more than 1,350 of these children had died. More than 80 percent of the children with AIDS were infected perinatally with the human immunodeficiency virus (HIV). Various studies have shown that 20 to 35 percent of children born to HIV-infected mothers in the United States are themselves infected *in utero* or at birth. Almost half of these children develop AIDS in their first year of life, with nearly 70 percent developing AIDS by the end of their second year. HIV-infected Black and Hispanic children comprise 84 percent of all pediatric AIDS cases.

HIV affects infants and children differently than adults. NIH is investigating the unique features of HIV infection and AIDS in infants, children, and adolescents, and working to develop treatments for this special population whose response to therapy can differ from that of the adult population.

The NIH AIDS research program is investigating the extent of the epidemic in women, infants, children, and adolescents; the transmission of HIV from mother to child; the effect of the virus on fetal and child development; treatment for infected children; approaches to better understand the behaviors and attitudes that contribute to the spread of AIDS; and methods to prevent the sexual transmission of the AIDS virus.

The National Institute of Allergy and Infectious Diseases (NIAID) leads the NIH effort on pediatric AIDS. Other institutes that support or conduct research in this area are the National Cancer Institute (NCI), the National Heart, Lung, and Blood Institute (NHLBI), the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Child Health and Human Development (NICHD), the National Center for Research Resources (NCRR), and the National Center for Nursing Research (NCNR).

National Institute of Allergy and Infectious Diseases

The number of children, women, and minorities infected with HIV continues to increase. As a result, the National Institute of Allergy and Infectious Diseases (NIAID) launched a new initiative to expand the number of AIDS Clinical Trials Units (ACTUs) that are studying AIDS therapies in children and to increase the ability of the existing network to enroll children and other underrepresented populations, such as women, minorities, and intravenous drug users. Fifteen sites now conduct pediatric clinical trials, and ten additional centers are now including children in drug efficacy trials. In addition to conducting scientifically sound clinical trials, participating sites will address the social, legal, and economic issues facing patients who may be economically or otherwise disadvantaged.

Recent AIDS Clinical Trials Group (ACTG) accomplishments in pediatrics include the completion of phase I (which assesses safety) and phase II (which is a pilot study to assess efficacy) clinical trials of AZT (azidothymidine), also known as zidovudine, in children. The studies were led by Dr. Gwendolyn Scott of the University of Miami, Florida, and Dr. Catherine Wilfert of Duke University, Raleigh, North Carolina, respectively. Data from these trials, efficacy data from other ACTG protocols (016 and 019), and the original Burroughs Wellcome efficacy trial of AZT provided the basis for approval by the Food and Drug Administration (FDA) of AZT therapy for children 3 months of age and older.

Pediatric clinical trials began in 1990 include a dose comparison phase II clinical study of a promising antiviral drug dideoxycytidine (ddC) and a study of CD4-IgG. (CD4 is the receptor on T cells to which HIV binds; IgG, of immunoglobulin G, is the main class of antibody proteins in the blood.) Recruitment has been completed for a study of the use of intravenous immunoglobulin in children receiving AZT, another important pediatric AIDS trial.

Mechanisms and Prevention of Perinatal Transmission Explored

Developing the means to prevent transmission of HIV from mother to infant is one of the highest priorities for pediatric research. An ongoing safety trial of AZT in pregnant women and a phase I clinical trial in infants will provide the necessary dose and safety data for further trials.

Learning more about the transmission of HIV from infected women to their infants is the major focus of the Women and Infant Transmission Study (WITS), which is cofunded by NIAID and NICHD. Approximately 700 HIV-infected pregnant women in New York, Boston, Chicago, and San Juan, Puerto Rico, are being recruited into WITS. This study will address several major research questions: how does HIV-associated immunosuppression affect pregnancy outcome; what is the natural history of HIV disease in

women; what factors influence HIV transmission from a mother to her fetus or infant; what is the natural history of HIV infection in the offspring of HIV-infected mothers; when during pregnancy does HIV transmission occur; and how can HIV infection in infants be detected shortly after birth. WITS will also evaluate neurodevelopmental effects of perinatally transmitted HIV infection. The results of this research should facilitate the early assessment of infection status in infants. The study will also examine the relationship between behaviors such as drug and alcohol use and perinatal transmission by recruiting women who acquired HIV infection through intravenous drug use or through heterosexual contact with intravenous drug users (IVDUs).

Another study, led by Dr. Edward Connor of the University of Medicine and Dentistry of New Jersey in Newark, will target the intravenous drug-using population in order to compare the natural history of pregnancies in HIV-infected women with noninfected women. Known as the "Newark Perinatal Study," it will include four groups of women: infected IVDUs, noninfected IVDUs, infected women who acquired HIV through heterosexual contact, and noninfected women at risk of HIV infection through heterosexual contact. The study includes drug-free women who are the sexual partners of HIV-infected men who may have acquired HIV through intravenous drug use.

NIAID grantees Dr. Paolo Miotti and Dr. Alfred Saah of the Johns Hopkins University, Baltimore, Maryland, in collaboration with investigators in Central Africa, have studied the prevalence and incidence of HIV infection as well as pregnancy outcomes in young pregnant women from urban Malawi. Overall, 17.6 percent of the 461 pregnant women studied were infected with HIV. The investigators found that women infected with HIV had a higher incidence of miscarriage than noninfected women. Infection rates seem to be increasing as well, with the annual incidence of HIV infection in the pregnant women rising from an estimated 4 percent per year between 1985 and 1987 to 7 to 13 percent between 1987 and 1989.

Dr. Thomas Quinn, NIAID intramural researcher, and colleagues, in collaboration with researchers from the Centers for Disease Control (CDC), Johns Hopkins University, and the Institute of Tropical Medicine in Antwerp, Belgium, have conducted studies of perinatal HIV infection in Zaire, Kenya, and Haiti. In these countries, 25 to 35 percent of the infants born to HIV-infected women become infected, and 70 percent of the infected infants die in the first 2 years of life. A beneficial effect of immunizations against commonly occurring childhood diseases was observed during the first year of life in HIV-infected children who survive; even though the infected infants' immune response to vaccination was lower than a normal response in healthy infants.

Research is also under way to determine the mechanisms by which HIV is transmitted from infected mothers to their infants.

NIAID intramural researchers Drs. Malcolm Martin, Wendy Maury, Barbara Potts, and Arnold Rabson have found that fetal placental tissue cells can be infected with HIV. The investigators hypothesize that direct placental infection by HIV may occur early in pregnancy. Since only some infants born to infected mothers develop AIDS, other factors may also play a role.

For example, studies evaluating women and infant pairs are looking for specific immune responses that may be involved in protecting infants from transmission of HIV from their mothers. Several NIAID- and NICHD-funded investigators, including Dr. Yair Devash and Dr. Ayre Rubinstein at Albert Einstein College of Medicine, the Bronx, New York, along with NCI scientist Dr. James Goedert and NICHD scientist Dr. Anne Willoughby, have reported that the presence of specific maternal antibodies to the surface protein (gp120) of HIV may correlate with evidence of reduced transmission of HIV from mother to child. If confirmed, this finding could provide a unique target for development of vaccines to prevent perinatal transmission. Understanding why some children are infected and others are not could aid in the development of treatment strategies to prevent the many cases of maternal-child transmission that do occur.

National Cancer Institute

A major focus of the AIDS efforts of the National Cancer Institute (NCI) is the search for safe and effective therapies for children with AIDS.

NCI scientists Drs. Phillips Pizzo, Karina Butler, David Poplack, and colleagues have carried out a pilot study of ddC in children. Studies in adults have shown that ddC can decrease the viral load, as measured by a decrease in viral p24 antigen. Unlike AZT, ddC does not appear to suppress bone marrow function. However, in adults, ddC causes skin rashes and mouth sores, and prolonged courses of treatment at higher doses may cause peripheral neuropathy, an uncomfortable and often painful condition of the extremities. To avoid this complication in children, the investigators used lower doses (four different levels) and limited use of ddC as a single agent to only eight weeks. No peripheral neuropathy was observed, and no dose-limiting bone marrow suppression occurred. However, mouth sores and rashes did develop at the higher doses. Eight of 15 children showed improved immune cell counts, and six of nine children who entered the study with elevated plasma levels of p24 (an HIV antigen) showed decreases in this parameter. Two of three children who had overt developmental deficits prior to beginning ddC treatment showed improvement.

The investigators have also evaluated a regimen in which AZT is administered to children for 3 out of every 4 weeks and ddC is administered during the fourth week. The goal of this schedule is to maintain continuous antiretroviral therapy while attempting to avoid the bone marrow suppression associated with AZT and the neuropathy seen with prolonged use of ddC. With the children now having been treated for at least 18 months, the pilot study appears to have accomplished this goal, suggesting that additional clinical trials with this regimen are warranted.

The researchers have also carried out extensive studies with dideoxyinosine (ddI), an analogue of ddC, and have shown it to be an active and promising antiretroviral agent in children. Present studies are comparing AZT to ddI, and evaluating AZT in combination with ddI.

National Heart, Lung, and Blood Institute

Research supported by the National Heart, Lung, and Blood Institute (NHLBI) is focusing the use of HIV antibodies to provide protection to infants born to HIV-infected mothers. Dr. Frederick Prince, a NHLBI contractor at the New York Blood Center in New York City, prepared an HIV-specific immunoglobulin (HIVIG) from the plasma of HIV-infected individuals who had high levels of circulating antibodies capable of neutralizing HIV in laboratory tests. The efficacy of the HIVIG in preventing HIV infection was tested in chimpanzees. The results suggest that HIVIG may be useful in passive immunotherapy for certain groups at risk of developing AIDS, such as babies born to HIV-infected mothers.

National Institute of Neurological Disorders and Stroke

An increasing number of infants and children are being damaged by neurological AIDS, particularly as it affects the development of brain function. Occasionally, and often in the earliest stages of HIV infection, nervous system damage is the only symptom. The National Institute of Neurological Disorders and Stroke is supporting research to determine how HIV damages the nervous system.

Research Uncovers Two Forms of Pediatric AIDS Dementia

NINDS-supported research is attempting to define and describe AIDS dementia, the mental deterioration that affects as many as 40 percent of AIDS patients, including infants and children. Grantee Dr. Clayton Wiley of the University of California, San Diego, has identified two types of pediatric AIDS dementia. In some affected children, the disease is progressive: they lose previously acquired skills, such as the ability to walk or talk. In others, the course plateaus: children maintain acquired skills but do not develop new skills as normally expected. Furthermore, Dr. Wiley has linked the progressive course to readily detectable levels of HIV proteins in the affected child's brain. In those with the plateau course, however, he has found little or no detectable HIV protein. These findings imply that ongoing infection of brain tissue with the AIDS virus leads to progressive brain damage, suggesting that therapies able to eliminate the virus might limit brain damage in infected children.

Neurological Consequences of HIV Infection Are Defined

Despite the prevalence of neurological involvement following HIV infection, it is unclear how the virus causes nervous system damage. Dr. Leon Epstein, institute grantee of the University of Rochester, New York, has identified elevated levels of an important immune substance called tumor necrosis factor (TNF) in pediatric AIDS patients. While comparing the cerebrospinal fluid of these patients, he also found that elevated TNF levels were more common in children with progressive AIDS dementia than in those without neurological involvement. Since earlier studies have shown that TNF can be toxic to myelin--a substance that coats and insulates nerves--Dr. Epstein's findings strengthen the hypothesis that high levels of TNF are one mechanism for HIV damage of nervous tissue.

National Institute of Child Health and Human Development

In keeping with its mandate to support health research on pregnancy and children, National Institute of Child Health and Human Development (NICHD) research on pediatric AIDS addresses a broad range of questions. These include how many children are born with AIDS; what are the features of AIDS in these children; how can AIDS transmission during pregnancy and childbirth be prevented; and how can young children with AIDS best be treated.

Studies Define Extent of Epidemic in Women and Children

The primary route of transmission of AIDS infection to children is from mother to child during pregnancy, labor and delivery. NICHD continues to support a study headed by Dr. George Grady at the State Laboratory of Massachusetts in Boston, which is screening routinely collected, paper-absorbed samples of neonatal blood for the presence of HIV antibody. This anonymous screening, which is being carried out in the northeastern United States and North Carolina, will make it possible to estimate the prevalence of HIV infection among childbearing women and their newborn children in these areas. Combined with similar information collected by the CDC, the NICHD data are being used to generate national seroprevalence estimates of the rate of HIV infection in childbearing women in the United States.

Research Targets Early Diagnosis of HIV Infection in Infants and Children

Current technology does not allow the accurate, early diagnosis of HIV-infected children born to HIV-infected women because of the presence of maternal antibody to HIV in newborn blood. NICHD is supporting research by six leading pediatric AIDS investigators who will examine ways to improve the reliability and validity of methods of early diagnosis of vertically transmitted HIV infection early in life. It is crucial that diagnostic technology be further refined and developed for two reasons. First, families at risk live for many months in the agony of not knowing whether or not their newborns are HIV-infected. Second, early diagnosis would make epidemiologic investigations and clinical trials far more efficient and cost-effective.

Clinical Treatment Attempts to Prevent Transmission of HIV Infection from Mother to Child

The pediatric clinical trials centers supported by both NICHD and NIAID have been working together to conduct research into effective ways to treat HIV infection in infants and children. This coordinated, cooperative effort expands the clinical trials sites and subjects available for state-of-the-art clinical trials and effectively offers facilitated access to these trials to the majority of HIV-infected children in the

United States.

Concomitantly, both NICHD and NIAID through NIAID's AIDS Clinical Trials Group have been working together to begin research into effective ways to prevent transmission of HIV infection from mother to infant. The clinical trials centers of both NICHD and NIAID have been expanded to include participation from gynecologists, obstetricians and other women's health specialists in the design and implementation of this research.

Research to prevent the transmission of HIV infection from mother to infant during pregnancy will explore the use of antivirals. NICHD has supported preclinical research in suitable animal models, such as the pregnant macaque monkey, to evaluate the safety and efficacy of antivirals given in pregnancy.

Like HIV-infected adults, children with the virus experience opportunistic infections as a result of impaired immune function. A 28-center NICHD-sponsored study recently showed that monthly administration of intravenous immunoglobulin (IVIG) reduces the development of serious bacterial infections in HIV-infected children whose immune systems have not already been severely impaired by the virus.

Immunoglobulin is a solution given intravenously that contains concentrated antibodies from normal human sera against various infections. Between March 1988 and October 1990, NICHD enrolled 372 children between the ages of 2 months and 12 years who had experienced symptoms as a result of HIV infection. In IVIG-treated children, treatment was shown to increase significantly the time free from serious bacterial infections, to reduce the number of overall bacterial infections, and to reduce the number of hospitalizations required in symptomatic HIV-infected children with CD4 lymphocyte counts of 200/mm³ or above (a measure of immune function). In children whose immune systems had been more severely impaired, reflected by CD4 counts below 200, no significant improvement was noted.

While the treatment is not a cure for pediatric AIDS, the investigators concluded that the treatment offers a means of preventing some of the serious complications of pediatric AIDS.

Natural History Study of HIV Infection in Hemophilia Begins

Dr. Edward Gomperts at Children's Hospital of Los Angeles is heading a study in coordination with NICHD, CDC and the Health Resources and Services Administration (NRSA) to determine the natural history of HIV infection in hemophilic children. In this study, hemophilic children who are seropositive for HIV infection, together with seronegative hemophilic controls and seronegative nonhemophilic sibling controls, will be followed over a 4-year period. Investigators will assess the children's growth and neurologic development and immunologic status, as well

as progression of the infection. This study has had an auspicious beginning, enrolling 330 children (71 percent of eligible patients) in 14 centers throughout the United States. Preliminary data analysis reveals higher than expected rate of neurodevelopmental and immunologic disability in the HIV-infected subjects. These findings await further description and confirmation.

The National Center for Research Resources

The National Center for Research Resources (NCRR), through its General Clinical Research Centers (GCRC) program, provides a research infrastructure for multidisciplinary studies on both children and adults. The GCRCs provide patient research facilities, computerized data management and analysis, and specialized laboratories for the translation of basic and clinical research into the medical practice, in addition to staff such as research nurses, dietitians, and biostatisticians. The number of research projects continues to increase markedly and pediatric studies for AIDS-related research has doubled during the past fiscal year. AIDS-related research is conducted at 80 percent of the GCRCs.

Outlook

As AIDS affects more and more women, research on the transmission of the disease to their offspring and on the development and treatment of AIDS in children becomes more important. New methods of early, accurate diagnosis derived from natural history studies on affected children will help ensure swift treatment for this age group. Clinical trials are expanding in order to identify therapies that are both safe and effective in the young. Basic research is also providing clues to ways in which HIV transmission from mother to child might be prevented, until broader efforts in AIDS research can effectively eliminate this disease as a risk for adults as well.

Centers for Disease ControlPEDIATRIC AIDS

Surveillance for pediatric HIV disease is being conducted through: 1) expanded efforts in national surveillance of HIV infection and AIDS in infants and children, including surveillance for all HIV infection in selected cities and States to better define the extent of the problem in this population; and 2) HIV seroprevalence surveys in neonates in 45 States and in young children attending outpatient clinics in the cities of New York, Washington, and Miami. Ongoing studies in Atlanta, New York, and Newark of children born to HIV-infected mothers are seeking to define risk factors for transmission of HIV from mother to child, evaluate new tests for diagnosis of HIV in infants, and better describe the course of the disease in infants. These children will also enter into treatment trials whenever possible. A study of women of childbearing age in a south Florida community with a high HIV prevalence is evaluating their sexual practices and possible approaches for supporting behavior change that will reduce the risk of infection in these women and their children.

Financial and technical support was provided to assess the behaviors associated with reproductive decision-making among women attending New York area gynecologic, prenatal and family planning clinics.

In addition, Perinatal HIV Prevention Projects have been funded to encourage the effective use of contraception among HIV-infected women and women at high risk of infection who wish to avoid pregnancy. Seven Perinatal AIDS Prevention Projects, totaling over \$5 million, were funded in fiscal year 1990 and will continue to be supported in fiscal year 1991. These projects will: 1) determine and seek to overcome obstacles to effective use of contraception among target populations; 2) facilitate the use of family planning services among the target population; 3) evaluate attitudinal factors related to use of contraception among HIV-infected and high-risk women; 4) encourage behavioral change among HIV-infected and high-risk women to reduce risk of acquisition or transmission of HIV.

ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION

Pediatric AIDS

There has been a dramatic increase in the number of AIDS cases among infants. AIDS is currently the ninth leading cause of death among children between the ages of 1-4 years. It is estimated that in 1991 one out of every ten pediatric hospital beds will be occupied by a child with AIDS. Minority children are currently over-represented among pediatric AIDS cases. Black children make up 53 percent of all childhood cases of AIDS, but represent only 15 percent of the Nation's children. Twenty-two percent of AIDS cases are found in Hispanic children, but they represent only 10 percent of the child population.

National Institute of Mental Health

NIMH is the focal point within the Public Health Service for research on behavioral and psychosocial aspects of human immunodeficiency virus (HIV) infection in infants and children. Knowledge developed in these areas will provide the basis for development of more effective preventive intervention programs and more practical and comprehensive educational and rehabilitation programs. NIMH studies will also contribute to improved diagnosis, treatment, and prevention of related brain conditions in infants and children, including prevention or reduction of developmental delays. Research on mental health needs of families with HIV infection, and the role of support systems and mental health services in facilitating coping in these families, will provide empirical data for development of effective emotional and social support as well as mental health services for affected families.

Accomplishments

The focus on pediatric HIV infection is relatively new within the NIMH AIDS program. Initial efforts have included reviews of the state of knowledge in behavioral and neuroscience aspects of HIV infection, identification of key research needs, and coordination with other PHS agencies. Extensive work has been undertaken to develop a program announcement on "Children with HIV Infection and AIDS" in collaboration with National Institute on Drug Abuse, National Institute Neurological Disorders and Stroke, National Institute of Child Health and Human Development, and National Center for Nursing Research. The Institute has also conducted a series of developmental activities, including establishment of an agency workgroup and convening of several meetings of experts, to establish a research agenda and facilitate research progress.

Current Activities

Animal Model

A group of intramural scientists, using SIV-infected juvenile rhesus macaques as a model for AIDS Dementia Complex, have shown that three of five infected monkeys were significantly impaired on one or more of the behavioral tasks designed to assess cognitive function and motor skill. This impairment occurs well before onset of clinical signs of immunodeficiency disease. These data indicate that SIV-infected juvenile macaques show neuropsychological changes similar to those seen in HIV-infected humans. This model is now being extended to neonatal macaques to better understand the infectious process following maternal-fetal transmission. It is hoped that this animal model will enable testing of potential therapeutic agents for inhibiting transmission of infection and retarding disease progression.

Immunology/Brain-Immune Interactions

NIMH supports research to understand regulation of immune response by the CNS and endocrine system. HIV attacks components of the immune system and renders the patient vulnerable to a host of diseases. More information is needed to understand effects of behavior on interactions among these systems and the role of repeated stressful events on immune function, especially in infants and children. A new project will study ways to prevent structural and functional changes in the central nervous system (CNS) that are caused by perinatal HIV infection. This study will examine and define immune responses to HIV of the fetus and neonate and compare them to responses of adults. The immune system performance that underlies the susceptibility of fetuses and neonates to HIV infection appears to be unique. Understanding this mechanism and resultant neurologic dysfunction may be crucial to devising new strategies to improve treatment. In FY 1991, NIMH will convene a meeting to assess the state of knowledge related to brain-immune interactions in HIV infection, including new findings related to infants and children.

Neuroscience Research

HIV infection of the nervous system occurs frequently and early in children. A major new project was initiated in FY 1990 to examine pathways by which HIV enters the brain and has its effect on the developing organism. This set of studies will explore whether there is a direct relationship between HIV and brain pathology. Studies using sophisticated microscopic techniques have demonstrated that fetal brain neurons growing in tissue culture undergo changes in number, shape, size and distribution of cellular structures after exposure to HIV. Ongoing studies of these neuropathologic changes may lead to a better understanding of mechanisms of HIV injury to cells of the CNS, and permit improved strategies for treatment and prevention of the neurological dysfunction associated with AIDS. Findings on infants and children may yield important information on the direct effect of HIV infection on the CNS and may also provide additional knowledge about how the adult brain is affected.

Work is also being supported to explore neurochemical and behavioral systems involvement in neonatal exposure. Differences may be attributable to varying impact of the virus on a developing nervous system. Understanding the role of HIV in the CNS will lead to improvement of treatment for HIV-infected children, including prevention or reduction of developmental delays.

NIMH is also funding several efforts to evaluate sequelae in children with prenatal HIV infection. One study is following 120 infants born to HIV-positive mothers. To date, this project has documented that 50 percent of these children experience neurodevelopmental delay and 10 percent exhibit acute onset of motor and cognitive difficulties. Even children who are born to seropositive women and later test seronegative seem to experience some impairment. This study should contribute to an understanding of the spectrum of neurological disease possibilities and should improve understanding of factors that predict neurological involvement.

Because infants and children are not always able to provide verbal diagnostic information and others may not provide reliable or complete information, NIMH took the lead in developing the Neuropsychological and Neurological Assessment Battery for Infants and Children with HIV Infection using a child developmental model. This measurement tool was created through a consensus development process entailing a series of meetings with experts in the field and representatives from other Federal agencies. NIMH plans to encourage use of this battery in cross-site comparisons of cognitive and neuropsychologic dysfunction in HIV-infected children. The National Institute of Allergy and Infectious Diseases AIDS Clinical Trial Groups may incorporate these tests into ongoing and future pediatric AIDS trials.

Behavioral Research: Risk Factors, Behavior Change, and Prevention

Current research studies of pregnant women and babies are seeking to identify women at risk for HIV infection and to follow HIV positive women through pregnancy. Other approaches are identifying neuropsychologic, neuropsychiatric, neurological and developmental problems of HIV infected babies and determining cofactors that predict probability of a seropositive mother having a seropositive child. Research will also document HIV onset and progression in infants and babies. Work is ongoing and planned to identify risk factors related to HIV positivity in both mothers and babies, how HIV infection expresses itself in women and children, why some babies become infected and others do not, and how current therapies for HIV infection affect the CNS in infants and children.

In FY 1989, NIMH cosponsored with National Institute of Child Health and Human Development an RFA on "Children's Understanding of AIDS." The Institute is supporting a set of studies aimed at

identifying how children acquire an understanding of the concepts of health and AIDS. A related effort has been examining concepts of human sexuality and mothers' views regarding the kind of information that is appropriate for children at different ages. A third study with twins will examine relative strength of environment and genetics in contributing to sexual orientation and high risk sexual behaviors. Information from these studies will be used to develop more effective individual, school, and community programs to reduce high risk HIV-related behaviors in children.

Information and Education: Health Care Workers and Providers

Health Care Worker Training contracts provide for training of health and mental health care workers in neuropsychiatric and psychosocial aspects of HIV infection and AIDS. These contracts have a particular emphasis on special populations, including infants and children, adolescents, minorities, women, and persons with severe mental illness. New training activities will continue to integrate mental health aspects of HIV related to infants, children and adolescents into primary health care training.

Clinical Health Services Research and Delivery

Research in related areas suggests that children with chronic illnesses and their families are at heightened risk for mental health problems because effects of poor physical health may interact with other risk factors for mental health problems, such as family disruption and poverty. This work provides guidance, but there are important differences regarding pediatric AIDS that require an innovative coordinated response. In the case of other chronic health problems, the child alone is ill and parents are able to care for him/her and any other children. Many HIV-infected children, however, are in single parent families. The mothers may be HIV-infected, have limited social support and poor self-esteem, and may be too ill to care for the child. If no one can assume the parental role, the child may face multiple disruptions in foster homes or institutional settings.

At the University of California at Los Angeles, an investigator is evaluating the impact of AIDS on difficulties in placement and adoption of HIV-positive infants who are dependents of the Juvenile Court. Another facet of this study is examining effects of uncertainties of care on mental health and coping abilities of caseworkers.

A coordinated research effort is needed to identify mental health services and psychosocial support that will most effectively remediate problems in children and their families. NIMH plans to stimulate research to: 1) identify mental health effects of HIV infection and AIDS on families, 2) identify coping mechanisms used by families living with HIV infection, and 3) design and evaluate mental health service and supportive systems of care to maximize functioning and minimize mental health problems in families with HIV infection. The study will use Medicare and

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Medicaid data to explore disease progression of babies who have multiple placements compared to those who have a stable living arrangement.

Research Manpower

To increase the numbers of investigators focused on pediatric AIDS, NIMH will provide support for institutional and individual research training programs. The need to recruit and to train investigators with HIV-related expertise in fields such as pediatric neurology, child psychiatry and developmental psychology was identified by the NIMH-sponsored CNS Pediatric meeting in March, 1990.

National Institute on Drug Abuse

Over 80 percent of all reported pediatric AIDS cases are attributed to transmission from a mother with, or at-risk for, HIV infection. Drug abuse is a major contributing factor in mother-to-child HIV transmission. One-half of pediatric AIDS cases linked to maternal transmission involve women who used drugs intravenously, and an additional 21 percent involve women with sexual partners who are injection drug users.

Mechanisms of transmission of HIV from mother to child is of primary interest. In addition, methods of early detection of HIV infection of the newborn and infant are vital to ensuring the earliest possible intervention to obtain the most favorable prognoses. Because the predominate technology for detecting HIV infection is based on the detection of antibodies to HIV, one of the major blocks to assessing infant infection is the presence of maternal antibodies to HIV in the infant for up to one year after birth. Research on methods to circumvent this difficulty are under investigation.

Recently Reported Data

This year a study was begun to determine the risk of developing symptomatic HIV infection and AIDS in a prospective study of infants born to seropositive mothers who are IV drug abusers or sexual partners of drug users. This project combines epidemiologic, clinical, virologic, and molecular biologic approaches in one setting. Virus isolation, detection of viral antigens, and polymerase chain reaction techniques are being developed to distinguish, as early in life as possible, infants who are truly infected from those with passive antibodies.

Data from three years of a five year prospective study designed to increase understanding of the transmission of HIV from mothers to infants, and to define the spectrum and developmental sequelae of HIV-induced disease, have been released. Study subjects are pregnant women at-risk for HIV infection and their children. To date, the project has followed 60 HIV-1 antibody-positive women. Thirty-seven of these women reported IV drug use as a risk behavior, and 12 reported having had a sex partner infected with/at-risk for HIV-1. Nine women died of AIDS; strikingly, 7 of these gave birth to children with symptomatic HIV-1 infection. Significant differences were reported in cognitive and motor development in eight HIV-positive infants compared with 19 seronegative infants born to mothers who were IV drug users. No significant differences were seen in social, language, and fine motor skills. Efforts at early diagnosis of HIV-1 infection by detection of IgA HIV-1 antibodies have been carried out in collaboration with other centers. The investigators report that the data suggest that presence of IgA antibody to HIV-1 may be a diagnostic marker for HIV-1 infection.

Preliminary analyses from a project designed to investigate characteristics of vertical transmission and associated disease

demonstrate the difficulty in determining which women are transmitters of HIV and the difficulty in interpreting symptomatic illness prior to 18 months of age. A transmission rate of approximately 30 percent was reported. The investigators concluded that the role of maternal HIV-1 antibody in preventing HIV-1 infection in infants requires further investigation. Preliminary results indicate that elevated maternal total and neutralizing HIV-1 antibody does not prevent perinatal HIV-1 infection. In addition, mothers who transmit HIV-1 to their offspring were not distinguishable by their plasma HIV-1 antigen levels, and that even children with normal CD4 lymphocyte number and ratios are at risk for developing AIDS related illness (e.g. pneumocystis carinii). Furthermore, other infections, e.g. cytomegalovirus, may be responsible for symptoms similar to those seen in HIV-1 infected infants (e.g. lymphadenopathy and hepatosplenomegaly disease) in at-risk children who may not be HIV-infected.

One other study of major interest reported this year on characteristics of women who are more likely to transmit HIV to their offspring. These data hold important implications for intervention and planning. The investigators have found that the risk of perinatal transmission increases with the presence of maternal sexually-transmitted diseases during pregnancy, and that women with surface glycoprotein, gp120, antibody have lower transmission rates. There is also evidence to suggest that women who transmit to their infants develop AIDS sooner than women who do not.

Strategies

The drug abuse prevention and treatment context offers the opportunity for intervention strategies aimed not only at drug use, but also directly at prevention of HIV infection (e.g., safer sex education, self-esteem development, empowerment training). Since HIV seropositivity surveys of women find the highest rates among IV drug users, treatment and prevention programs targeted towards this population offer a strategic point of intervention for preventing the perinatal transmission of AIDS. In addition, there is also evidence that other drug use (non-IV) is correlated with sexual activities that place persons at risk for HIV infection. The processes by which drug use mediates risk (e.g., disinhibition) are currently undergoing investigation. The impact of the use of crack cocaine on HIV infection remains unknown at this time. Additionally, special efforts may be necessary to reach women who themselves are not IV drug users, but who are the sexual partners of IV drug users.

Ongoing drug treatment and prevention projects are examining a wide array of services and service delivery models. Areas of attention include the challenges of identification of at-risk persons, outreach, and retention; the multiple needs of the population (e.g., substance abuse education, psychosocial support, prenatal care, safe housing, vocational training, transportation, and child care services), any of which may

influence participation in and effectiveness of a prevention or treatment program; legal issues; and staff training.

Although drug-abusing women may be difficult to locate and maintain in traditional therapeutic programs, reports from a number of clinical studies suggest that recruitment and retention would be enhanced if a continuum of care via therapeutic programs along with comprehensive supportive services and extensive community outreach were provided. Among the principles being emphasized in the drug treatment and prevention projects currently underway are: (1) a family orientation for programs, with a broad definition of family, (2) inclusion of child care services in programs, (3) use of a range of services with varying levels of intensity, (4) close coordination among service agencies and systems, (5) use of in-home and center-based program components, and (6) utilization of multidisciplinary teams.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Maternal and Child Health Bureau

Pediatric AIDS

The Pediatric AIDS Health Care Demonstration program is designed to demonstrate effective ways to prevent infection, especially through the reduction of perinatal transmission; develop community based, family centered, coordinated services for infected infants and children; and develop programs to reduce the spread of HIV infection to vulnerable populations of young people. The occurrence of HIV infection in the pediatric populations is rapidly increasing (40% increase from November 1989 to November 1990). This program complements the Ryan White CARE Act in that it will provide needed services to areas of emerging HIV incidence that would not otherwise be eligible for assistance under the Ryan White CARE Act.

In addition to the Pediatric AIDS Program the Maternal and Child Health Bureau will provide technical assistance and consultation to the States for carrying out the provisions relating to pediatric AIDS, of the Ryan White CARE Act.

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

PEDIATRIC ACQUIRED IMMUNODEFICIENCY SYNDROME

The purpose of the Agency for Health Care Policy and Research (AHCPR) is to enhance the quality, appropriateness, and effectiveness of health care services and to improve access to that care. This is accomplished through the establishment of a broad base of scientific research and through the promotion of improvements in clinical practice and in the organization, financing, and delivery of health care services. The AHCPR also is responsible for facilitating the development, review, and updating of clinically relevant guidelines for specific conditions and treatments. As the focal point of Federal efforts in medical effectiveness and health services research, the AHCPR seeks to create and disseminate new knowledge and better understanding of the processes by which health services are made available and how they may be provided more efficiently and effectively. It addresses the full array of health care issues, among them pediatrics AIDS.

General Health Services Extramural Research

The Agency's Center for General Health Services Extramural Research has a multi-faceted approach to HIV health services research (see separate Moyer submission on AIDS). The centerpiece of this program is the support of research, through peer-reviewed grants and contracts. In addition, the extramural research program provides extensive technical assistance and policy analysis, facilitates timely dissemination of research findings, and works collaboratively with all concerned to assure that activities are coordinated.

Projects Addressing Pediatric AIDS Issues:

Allison-Cooke, Sherry, Ph.D., National Perinatal Information Center, "Pediatric AIDS: Local Responses, Service Use, and Cost," Grant No. HS 06271

This project will provide both longitudinal and cross-sectional data about the utilization and costs of inpatient and outpatient care for infants, children, and women with AIDS. One aspect focuses on discharge, billing, and cost data from 10 hospitals in 5 urban areas with high incidence of pediatric AIDS and will analyze trends from 1987 to 1991. In addition, detailed case studies will be developed to address questions about alternate community responses to meeting the health care needs of women and children with AIDS and to obtain information on outpatient services.

Turner, Barbara; Thomas Jefferson University, School of Medicine, "Consequences of Patterns of Provider Care for AIDS," Grant No. HS 06465

This project will examine specific patterns of outpatient provider care for AIDS patients of all ages who are New York or California Medicaid enrollees. Four groups of Medicaid enrollees will be studied: homosexual or intravenous drug user (IVDU) men, women, and children. A severity of illness index will be developed for children with AIDS following a similar process used for adults.

"AIDS Cost and Service Utilization Survey" (ACSUS) Westat, Inc., Rockville, MD, Contract No. 282-89-0020

ACSUS is a national survey to collect uniform data on the utilization and costs of health and social services for persons with AIDS and other HIV-related illnesses. Interviews will be conducted every 3 months over an 18-month period, with a sample of approximately 1900 adults and adolescents plus 100 children. In addition to medical care, respondents will be asked about their use of social, mental health, and oral health services, informal social supports, barriers to care, employment history, and quality of life. Interview data will be supplemented by information abstracted from patient records and information supplied by providers and insurers.

These sources will provide a comprehensive picture of the direct and indirect costs of medical and support services, during various stages of HIV-related illness. Data will include third-party and out-of-pocket payments, for both inpatient and outpatient care, including care received in physicians' offices, ambulatory clinics, and the patient's home. Utilization and charges for the services of physicians, nurses, and other health care workers will be obtained, as will charges for drugs, medical supplies, and devices.

Final products of the contract will include documented data tapes for use by the research community. In addition, ACSUS data will enhance AHCPR's capacity to provide timely input to policy questions. The data will support examination of utilization, cost, and access across HIV exposure categories (e.g., homosexual, heterosexual, or intravenous drug use), stage of illness, demographic characteristics, geographic area, and payment source. By addressing the full spectrum of HIV-related illness and the range of health care providers and payers, ACSUS will provide a rich source of data for research and the basis for policy-relevant analyses concerning the utilization and costs of health care services associated with HIV illness.

HEALTH CARE FINANCING ADMINISTRATION

PEDIATRIC ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)Part I - Background

HCFA addresses pediatric AIDS as a component of its overall AIDS initiative; thus, the background information supplied for these reports under the general AIDS heading is also relevant for pediatric AIDS.

Up to 90 percent of children perinatally infected with the human immunodeficiency virus (HIV) are eligible for and have their medical care covered by Medicaid. Their eligibility may derive from their mothers' receipt of cash assistance under the Aid to Families with Dependent Children program, by virtue of their disability under the Supplemental Security Income program, or from the status of a poverty-related pregnant woman or child. Some States offer a medically needy program for which individuals "spend down", incurring medical costs which deplete their resources for medical expenses. Medicaid AIDS caseloads are likely to grow with increasing rates of reported cases among pregnant women, infants, and children.

Services that are mandatory for the general Medicaid population are available to eligible children with AIDS. In addition, all States must cover early and periodic screening, diagnostic and treatment services for Medicaid eligible individuals under 21. State Medicaid agencies must seek out eligible children and families to encourage their enrollment in this preventive and comprehensive health program. State Medicaid agencies must inform eligible persons regarding the benefits of prevention and the availability of services and assist them with scheduling and transportation. These agencies must also assure that the health needs of eligible children are assessed through initial and periodic examinations and that detected health problems are diagnosed and treated early before they become more complex and their treatment more costly.

EPSDT screening services include a comprehensive health and developmental history, a comprehensive unclothed physical examination, appropriate immunizations, laboratory tests, and health education and guidance. Other required EPSDT services include vision, dental, and hearing services, and other necessary health care, diagnostic services, and treatment available under Medicaid.

The Omnibus Budget Reconciliation Act of 1989 (OBRA) expanded eligibility for EPSDT by extending Medicaid coverage to children up to age 6 in families with incomes up to 133 percent of the Federal poverty level. (Effective July 1, 1991 OBRA 90 requires States to cover children up to age 19 born after September 30, 1983 in families with income up to 100 percent of poverty.)

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In addition, blood lead level testing and health education and guidance must be included among EPSDT screening services. States must establish distinct periodicity schedules for screening, dental, vision, and hearing services and are required to cover medically necessary interperiodic screening. States may not limit qualified providers to those who can furnish all EPSDT services.

OBRA 89 also requires States to cover necessary Medicaid health services to correct or ameliorate conditions discovered by screening, whether or not these services are covered under the State Medicaid plan. This provision permits eligible children with AIDS access to the fullest range of diagnostic and treatment services available through Medicaid.

Medicaid AIDS-related services covered at State option, such as targeted case management services and prescribed drugs, may also serve children with AIDS. Home- and community-based services waivers in California, Florida, Hawaii, Illinois, New Jersey, and South Carolina cover enhanced foster care for children with AIDS or HIV infection. New York State's concept of designated AIDS care centers has been extended with the establishment of pediatric and maternal centers based in the 21 hospitals statewide already designated to serve the general adult population.

HCFA is represented on the U.S. Public Health Service Panel on Women, Adolescents, and Children with HIV Infection and AIDS. HCFA's Boston Regional Office has cosponsored two regional pediatric AIDS conferences with other HHS agencies.

Part II - Program Data

HCFA estimates of Medicaid and Medicare AIDS-related costs and numbers of individuals, furnished under the general AIDS heading, do not distinguish between overall and pediatric program data.

OFFICE OF HUMAN DEVELOPMENT SERVICES

Pediatric Acquired Immunodeficiency Syndrome

- The Abandoned Infants Assistance program provides financial support to public and non-profit private entities to develop, implement, and operate demonstration projects to prevent the abandonment of infants and young children, particularly those who have been exposed to HIV, AIDS or maternal drug abuse. (Note: There is a significant overlap between those who are HIV and drug exposed. The total funding for this program has been included in HIV/AIDS related expenditures.)

In fiscal year 1990, 17 model comprehensive service projects to include foster family care, case management, family support services, respite and crisis intervention, and counseling; five cross-disciplinary training projects; two resource development and coordination projects to assist States and localities to develop innovative approaches for use of funds obtained from different funding sources for coordinated services; and five coordinated early intervention for HIV positive children at high risk for developmental disabilities were funded to improve services and prevent abandonment of young children exposed to or suffering from AIDS or maternal drug abuse. In addition, under an Interagency Agreement with the Bureau of Maternal and Child Health, supplements were made to 12 Pediatric AIDS Demonstration Centers to augment services to prevent the abandonment of infants or young children. These efforts will be continued in fiscal years 1991 and 1992. In addition, it is anticipated that two resource centers will be funded for technical assistance, monitoring, evaluation, and other services to grantees.

- Four child welfare demonstration projects focusing on the social service needs of HIV-infected children and their families, particularly those in the foster care system, initially funded in fiscal year 1988, were continued for a total of \$894,018 in fiscal year 1990.
- Four projects targeting HIV-infected Head Start children and their families, initially funded in prior years, were continued for a total of \$855,000 in fiscal year 1990.
- Two projects to help overcome barriers to services and to provide guidance on procedures for handling confidentiality issues with special attention to developmentally disabled persons exposed to HIV, initially funded in fiscal year 1988, were continued in fiscal year 1990.

Pediatric Acquired Immunodeficiency Syndrome, page 2

- Four (of twenty-two) projects funded in fiscal year 1990 under the Temporary Child Care for Children With Disabilities and Chronically Ill Children and Crisis Nurseries program made specific reference to services for HIV positive children or those with AIDS. Potentially some of the remaining eighteen projects could also serve this population.
- States may also use funds provided under the Social Services Block Grant (SSBG), Child Welfare State Grants, Child Abuse and Neglect State Grants, and Family Violence State Grants for services to HIV positive children or those with AIDS. However, States are not required to report on the use of these Federal funds in such manner as to permit estimates of the amounts used in connection with substance abuse. Similarly, substantial Federal outlays are used to support children who are placed in foster care, a condition frequently associated with substance abuse in the home.

Summary of HDS Pediatric AIDS Expenditures

1990 actual	1991 estimated	1992 estimated
\$12,677,858	\$13,157,000	\$13,157,000

Basis for Summary Numbers:

	1990 actual	1991 & 1992 estimated
Abandoned Infants	\$ 9,867,000	\$12,557,000
Child Welfare	894,018	-0-
Head Start	925,000	-0-
ADD	400,842	-0-
Temp. Care/Crisis Nurseries	590,998	600,000
	\$12,677,858	\$13,157,000

RURAL HEALTH
OBLIGATIONS

	<u>1988</u> <u>Actual</u>	<u>1989</u> <u>Actual</u>	<u>1990</u> <u>Actual</u>	<u>1991</u> <u>Cong Allow</u>	<u>1992</u> <u>Pres Budget</u>
<u>Public Health Service:</u>					
Centers for Disease Control	\$1,600,000	\$1,600,000	\$13,052,000	\$20,522,000	\$20,522,000
Agency for Health Care Policy and Research.....	\$300,000	\$679,000	\$4,009,000	\$3,416,000	\$4,279,000
<u>Alcohol & Drug Abuse and Mental Health Administration</u>	\$1,566,000	\$7,010,000	\$18,234,000	\$25,606,000	\$27,597,000
<u>Health Resources & Services Administration:</u>					
Bureau of Health Care Delivery and Assistance....	\$215,200,000	\$231,931,000	\$258,545,000	\$273,179,000	\$265,005,000
Bureau of Health Professionals.....	5,441,992	10,301,042	14,195,524	15,657,889	---
Office of the Administrator	<u>1,436,000</u>	<u>1,482,000</u>	<u>3,380,000</u>	<u>24,192,000</u>	<u>4,139,000</u>
Total, HRSA.....	\$222,077,992	\$243,714,042	\$276,120,524	\$313,028,889	\$269,144,000
<u>National Institutes of Health:</u>					
National Cancer Institute...	\$10,300,000	\$13,947,000	\$17,465,000	\$18,001,000	\$18,410,000
National Heart, Lung, and Blood Institute.....	1,971,000	2,159,000	2,097,000	2,200,000	2,350,000
National Institute of Dental Research.....	854,000	886,000	973,000	1,070,000	1,170,000
National Institute of Environ- mental Health Sciences.....			626,000	730,000	759,000
National Institute on Aging	1,653,000	1,785,000	2,150,000	5,007,000	5,257,000
National Center for Nursing Research.....	1,092,000	1,461,000	1,722,000	2,800,000	3,100,000
National Library of Medicine	<u>0</u>	<u>1,800,000</u>	<u>3,813,000</u>	<u>5,533,000</u>	<u>6,479,000</u>
Total, NIH.....	\$15,870,000	\$22,038,000	\$28,846,000	\$35,341,000	\$37,525,000
1, PHS.....	\$241,413,992	\$275,041,041	\$340,261,524	\$397,913,889	\$359,067,000

CENTERS FOR DISEASE CONTROL
NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND HEALTH

Rural Health

Agricultural workers and their families experience a disproportionate share of injuries and diseases associated with numerous chemical, biological, and physical hazards.

In FY 1990, NIOSH expanded activities in various specific ways for a national program to address the disease and injury problems in agriculture.

Using agricultural initiative resources appropriated by Congress in FY 1990, NIOSH developed a coordinated program of surveillance, research, and prevention activities. This program is being expanded in FY 1991. These include:

SURVEILLANCE

FARM FAMILY HEALTH AND HAZARD SURVEY: to determine to which hazards agricultural workers and their families are potentially exposed, the circumstances of exposures, and the health status of these workers and their families. This effort is currently being administered through six cooperative agreements and will be increased by 3-5 awards in FY 1991.

PUBLIC HEALTH NURSES IN RURAL COMMUNITIES: nurses in 30 - 50 rural hospitals nationwide will: (1) work with county Extension agents and rural families to promote safety and health; (2) report agriculture-related disease and injury cases to the States and NIOSH; (3) provide safety and health instruction in high schools and vocational agriculture schools; (4) assist county and State Health Departments in surveillance and hazard evaluation. In FY 1990, eight cooperative agreements were awarded for this activity. In FY 1991, this program will be expanded by 3-5 awards.

INJURY SURVEILLANCE: (1) NIOSH is expanding the "Traumatic Injury Surveillance of Farmers" (TISF) project, which will be a mail survey, conducted in conjunction with land grant universities, to obtain national and State disability prevalence, injury incidence, and exposure information. (2) Complementing TISF, NIOSH and CEHIC, through NCHS in a special supplement to HIS, will obtain information to estimate total injuries, for workers and their family members, related to agricultural work.

RESEARCH

AGRICULTURAL CENTERS: In FY 1990, NIOSH awarded cooperative agreements for the establishment of two centers for agricultural safety and health. They will conduct research, develop model educational programs, develop model prevention programs, assist and evaluate prevention programs implemented by the Agricultural Health Promotion System and others, devise and evaluate

engineering and ergonomic technology, and provide consultation. In FY 1991, an additional center will be established.

LUNG DISEASE RESEARCH: In FY 1991, NIOSH will continue to conduct laboratory and field research related to adverse respiratory effects from selected agricultural dusts.

In FY 1992, NIOSH will continue developing a coordinated program of surveillance, research, and prevention activities, by continuing the projects initiated in 1990.

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

RURAL HEALTH CARE

The purpose of the Agency for Health Care Policy and Research (AHCPR) is to enhance the quality, appropriateness, and effectiveness of health care services and to improve access to that care. This is accomplished through the establishment of a broad base of scientific research and through the promotion of improvements in clinical practice and in the organization, financing, and delivery of health care services. The AHCPR also is responsible for facilitating the development, review, and updating of clinically relevant guidelines for specific conditions and treatments. As the focal point of Federal efforts in medical effectiveness and health services research, the AHCPR seeks to create and disseminate new knowledge and better understanding of the processes by which health services are made available and how they may be provided more efficiently and effectively. The AHCPR addresses the full array of health care issues, among them rural health care.

Rural health care continues to be an area of special emphasis for the Agency for Health Care Policy and Research (AHCPR). In creating the new Agency, OBRA 1989 (P.L. 101-239) requires that, in carrying out the activities of Title IX of the PHS Act, AHCPR undertake and support research, demonstration projects, and evaluations with respect to the delivery of health care services in rural areas (including frontier areas).

Health services research on the delivery of health care services in rural areas is needed for many reasons. There are major differences in the organization and use of health care resources between rural and urban areas. The number of physicians per capita, the number of hospitals and other institutional facilities per square mile, the extent of public control of health facilities, the travel time to obtain health care services and the use and complexity of health care services differ between rural and urban areas. The population served by rural hospitals also is different from that treated in urban hospitals. Rural hospital patients are older, are less likely to be on Medicaid or to be self-paying, and are admitted with diagnoses that require longer hospital stays on average. In addition to all of these difficulties, present economic conditions are having an effect the provision of adequate health care services to rural and frontier areas of this country.

In FY 1989-FY 1991, funds were appropriated to the Agency to continue and expand research on the rural health services research agenda developed during the FY 1987 conference on rural health issues.

General Health Services Extramural Research

The Agency's Center for General Health Services Extramural Research has a multi-faceted approach to research on rural health care. The centerpiece of this program is the support of research through peer-reviewed grants and contracts. In addition, the Center provides extensive technical assistance and policy analysis, facilitates timely dissemination of research findings, and works collaboratively with all concerned to assure that activities are coordinated.

In May of 1990 at the Annual Conference of the National Rural Health Research Association in New Orleans, the Agency funded a special session on "Submitting a Successful Rural Research Grant Proposal." Two other technical assistance conferences were co-funded by AHCPR and the Health Resources and Services Administration (HRSA).

Both AHCPR and HRSA are well aware that there is a need to provide greater technical assistance to rural researchers who have little experience in obtaining funding from government agencies or private foundations. Such experience is reflected in the significant number of grant applications received from rural health researchers which are judged to be marginally acceptable or not acceptable for funding. The Rural Health Research Centers, which are to collect and analyze information, conduct applied research on rural health issues and to widely disseminate results, were felt to be the logical vehicle through which to provide technical assistance to potential rural health researchers.

The first of two conferences was held September 10-11, 1990, conducted by the North Carolina Rural Health Research Program at the University of North Carolina in Chapel Hill, N.C. Participants were drawn mainly from the Southeast region. The second conference, held September 17-18, 1990, was conducted by the WAMI Rural Health Research Center at the University of Washington in Seattle, Washington. That conference attracted participants from the region around the State of Washington.

These technical assistance conferences are part of a series of such conferences planned around the country to assist individuals who are interested in developing rural research projects. The conferences' primary goal is to stimulate the development of new research and enhance the quality of existing research projects which focus on rural health services. In 1991, three more such conferences at rural health centers will be sponsored jointly by AHCPR and HRSA in Marshfield, Wisconsin, Grand Forks, North Dakota, and Tucson, Arizona.

Technical assistance presentations for potential grantees also will be held at the annual meeting of the Association of University Programs in Hospital Administration in March 1991 in Washington, D.C. This program is focused on attracting researchers from smaller hospitals. A technical assistance session also will be

arranged at the 14th Annual Conference of the National Rural Health Association in May 1991 in Seattle, Washington.

Projects Ongoing in Fiscal Year 1990:

"Health Services Impact of Community Health Centers (CHC) Use in Rural Maine,"

Ronald Deprez, Ph.D., Medical Care Development, Inc., Grant No. HS 05756

Rural Community Health Centers are private, nonprofit, fee-for-service health care organizations which provide comprehensive services to residents of rural areas. Some of these centers are located in areas which qualify for Federal reimbursement of costs on the basis of need. Maine contains 32 CHCs, of which 18 rural CHCs receive Federal funds.

The objectives of this study are to examine the influence of provider, setting, and patient characteristics on hospital utilization in rural areas in Maine served by Community Health Centers (CHCs) and to assess the policy implications of those observations on Federal efforts to provide access to primary care in rural areas. Only the 18 Federally supported CHCs are included in this study.

The aims of this study are to determine (1) to what extent CHC use substitutes for hospital use, and for which population and diagnoses, after controlling for population and provider characteristics, (2) to what extent organizational and financing characteristics of primary care delivered in CHCs are responsible for the substitutive effect, (3) to what extent variation in hospital use is influenced by provider and/or practice compensation methods, and (4) how payment methods for physician and outpatient services in rural areas might be revised to achieve reduction in hospital use without sacrifice of quality of care by rural populations.

This research is a follow-up to a study conducted in 1984 by Medical Care Development (MCD) in which significant differences were observed in hospital utilization rates between users and nonusers of CHCs in rural Maine, suggesting a substitutive effect of CHC use for inpatient hospital care.

"The Rural HMSA Physician Retention Study,"

Thomas R. Konrad, Ph.D., University of North Carolina, Grant No. HS 06544

The purpose of this investigation is to provide information about the understanding of current physicians in rural health manpower shortage areas (HMSAs), with an emphasis on physicians in the National Health Service Corps (NHSC). The study has six specific aims: (1) to describe a current cohort of physicians working in rural HMSAs, their personal

characteristics, work motivations, content of clinical practice, and retention plans, comparing those in the NHSC with non-NHSC physicians; (2) to define the determinants of recruitment and retention of current NHSC and non-NHSC physicians in rural practice in health manpower shortage areas; (3) to assess the physicians; (4) to recommend future effective retention policies for NHSC and non-NHSC physicians in rural HMSAs; (5) to clarify conceptual and methodological issues involved in measuring rural physician retention; and (6) to identify a cohort of physicians who are recent entrants into rural practice and compile information about them into a database for future descriptive and analytical longitudinal studies.

The issue of access to health care services in rural areas is a major, on-going concern. The NHSC deployment program is a major initiative to meet this need. The extent to which NHSC physicians and non-NHSC physicians, who may or may not have established practices in rural areas as a result of the doctor surplus, and whether they intend to remain there, is an important policy issue.

"Urban/Rural Differences in Elderly Use of Long-Term Care"

Dr. Charles McConnel, University of Texas Southwestern Medical Center, Grant No. HS 06197

Dr. McConnel will establish the extent and determinants of differences in survival and utilization of health and community based services by the rural/urban elderly. Data from the Longitudinal Study of Aging, the Census of the Population, the National Death Index, and the Health Professionals Resource File will be linked. A single analysis will then link a defined population data by health status, health services access, and health services utilization. The outcome variables include: physician visits, nursing home admissions, home health and/or nursing visits, homemaker services, use of community services and hospitalization.

"Rural Hospital Management Strategies and Viability"

Stephen Mick, Ph.D., University of Michigan (formerly of Johns Hopkins University), Grant No. HS 05996

This study will examine the determinants, characteristics, and impacts of strategic management responses by rural hospitals to changes in their environment during the 1980s. The results of this study will provide knowledge about relationships between [1] changes in payment systems and local economic conditions during the 1980s and [2] rural hospital management strategies and economic performance. Evidence about the relative effectiveness of various management strategies may help rural hospitals adapt to their changing environment.

"Alternative Health Care Utilization in the Rural Elderly"

Dr. James Mitchell, East Carolina University, Grant No. HS 05381

Dr. Mitchell will describe and model the use of alternative health care resources by rural poor and black elderly. The variables which influence alternative care use will be identified. Seven hundred and ninety-eight rural poor and black will be identified in 10 of the 33 officially designated rural counties in North Carolina. All respondents identified in a personal interview as users of alternative care will again be interviewed in the home. The study will identify the reasons for alternative care by rural poor and black elderly and provide clues as to the dynamics of their health care utilization.

"Access to Medical Care Among the Indigent in Nebraska"

Keith Mueller, Ph.D., University of Nebraska, Grant No. HS 05760

Dr. Mueller will identify the problems of access among the uninsured in rural areas and they will be compared to the difficulties in access to care for the medically indigent in urban areas. The number of medically indigent in Nebraska will be determined as well as their geographic distribution. This study will identify the changes in the number of uninsured in Nebraska since the recession and financial crisis in the agricultural economy in 1982-1983. Data will be collected through telephone surveys. Correlation analysis will be used to determine relationships between the dependent variables of income levels, county of residence, age, and occupation. Multiple regression analyses (including path) will be used to explain the incidence of medical indigence.

New Starts in Fiscal Year 1990:**"Multilevel Practice Model for Rural Hispanics,"**

Sandra L. Ferketich, Ph.D., University of Arizona, Grant No. HS 06891

This research proposes to evaluate the success of a three-tiered community-based nursing delivery model, the Comprehensive Multi-level Nursing Practice Model, among Hispanics in a rural community setting. This model will be operationalized in the Mexican American community in rural Pinal County, Arizona. The demonstration component will develop and implement three nursing interventions: personal preventive nursing, organized indigenous caregiving, and community empowerment. The focus of both the model and the interventions is on improving the health of the population by directing the interventions to individuals and families, groups, and the community.

"Controlled Trial of a Health Maintenance Tracking System"

Paul S. Frame, M.D., Tri-County Family Medicine, Grant No. HS 06283

This project will compare the effects of a computerized tracking system for health maintenance with a manual flowsheet-based system in four primary care offices in rural western New York State. The specific health maintenance procedures to be studied are tobacco use history, serum cholesterol on patients less than age 70, blood pressure on all patients, fecal occult blood testing on persons older than age 40, physician breast examination for all women, mammography for women over age 50, and Papanicolaou smears on women less than age 70. The hypothesis to be tested is that in comparison with a manual system, a computerized reminder system for health maintenance will be better utilized by physicians, improve compliance with health maintenance recommendations among the entire patient population and will be more effective in getting inactive patients involved in health maintenance.

"Local and Non-Local Hospital Use by Rural Iowans"

Ann E. Mowery, Iowa State University, Grant No. HS 06790

This project will describe the scope of and explain the reasons for outmigration from rural Iowa communities, with small hospitals, to more distant urban hospitals--it will describe the characteristics of those who leave for care outside their communities and the characteristics of the hospitals they leave and the hospitals they choose. This will be accomplished through a cross sectional analysis of 170,000 hospitalizations from 88 rural counties in Iowa's 126 hospitals in 1988.

The economic problems of rural hospitals, with their implications for the cost and quality of and access to hospital care, are high on the health policy agenda. The amount of empirical information on the determinants of rural consumer choice between local and distant hospitals, however is limited. Although this proposal is limited to one state, it is one in which the rural hospital problem is more acute. Thus, the results of this study will have some relevance to the national debate.

"Nursing Interventions to Improve UPSTATE Testing"

Maija L. Selby, Dr. P.H., R.N., University of North Carolina, Grant No. HS 06507

The long term goals of this study are to improve health and reduce health care costs for children of low-income families by increasing utilization of Early and Periodic Screening, Diagnosis and Treatment (UPSTATE), a federal program of comprehensive health promotion and disease prevention services for Medicaid-eligible children from birth

to age 21. The specific aim of the study is to test the effectiveness, cost-effectiveness, and efficacy of Public Health nursing interventions to improve utilization of UPSTATE in rural North Carolina.

General Health Services Intramural Research

The Agency's General Health Services Intramural Research Center also is examining issues relating to rural health care. The National Medical Expenditure Survey will provide a unique, updated data base for the analysis of how the population (including rural Americans) uses health care, what they pay for this care, and how expenditures are financed.

Another component of the intramural program, the Division of Provider Studies, is analyzing comparisons of rural hospitals with their urban counterparts along a number of dimensions such as environment, service mix, and staffing patterns for all U.S. hospitals. Using about 400 hospitals within the Hospital Cost and Utilization Project (HCUP) sample, rural and urban hospitals are being compared in terms of case mix, financial position, and utilization of these institutions. In FY 1990, two analyses using the second HCUP data base (containing summary abstracts of all patient discharges from the hospitals contained in the sample during 1980-1987) addressed rural health concerns:

Authors: Lemrow, Nancy; Adams, David; Coffey, Rosanna; and Farley, Dean
 Title: The 50 Most-Frequent Diagnosis-Related Groups (DRGs), Diagnoses, and Procedures: Statistics by Hospital Size and Location
 Source: Hospital Cost and Utilization Project

Authors: Rizzo, John
 Title: Is Medicare a "Bad Deal" for Rural Hospitals?
 Source: Working Paper, Division of Provider Studies, CGHSIR, AHCPR

User Liaison Program

The User Liaison Program was established to convey relevant and timely health services research findings and related information to state and local government policymakers in a manner that allows such officials to absorb this information and thus heighten the possibility of research being employed in the decision making process. One of the Program's main functions is to identify pressing informational needs of state and local government officials that could be addressed by new health services research studies or by syntheses of existing research findings.

The issue of rural health care was the subject of three User Liaison Program workshops held in Idaho, Alabama, and Vermont during calendar year 1990. Earlier workshops on this topic were held in Oregon, Texas and upstate New York. Staff of the Office of Rural Health Policy in the Health Resources and Services Administration (HRSA) assisted in the planning of these workshops and have been active participants in several of them.

Medical Treatment Effectiveness/Outcomes Research

The goal of the AHCPR's Medical Treatment Effectiveness Program (MEDTEP) is improved effectiveness and appropriateness of clinical practice. The Agency helps to generate scientific and policy-relevant information on the effectiveness of alternative strategies for the prevention, diagnosis, treatment, and management of a wide variety of acute and chronic conditions. In FY 1990, two projects were supported through MEDTEP relating to rural health care. These include:

"Practice Variations in Prenatal and Intrapartum Care"

Roger A. Rosenblatt, M.D., University of Washington, Grant No. HS 06166

This study will explore the relationship between variations in prenatal care received by low risk women in Washington State to provider type (obstetrician, family practitioner, nurse practitioner), location (urban/rural), practice organization and hospital setting. Outcomes to be collected include perinatal mortality, morbidity, and charges. The results will assist in decisions regarding appropriate utilization of prenatal technology for low risk women.

"Gastroenteritis Patient Outcome Research"

Christy Moynihan, Ph.D., SysMetrics/McGraw-Hill, Inc., Contract No. 282-90-0043

The contractor will evaluate the available literature and data on pediatric gastroenteritis and collect and analyze data to evaluate variations in treatment, outcomes, and resource use. The study population will include American Indian and Alaskan Native populations. Clinical recommendations will be developed based on findings.

ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION

Rural Health

National Institute of Mental Health

About one-fourth of the U.S. population lives in rural areas--nearly 65 million people. Although rural Americans are subject to the same serious mental illnesses that affect the general population, the farm crisis of the 1980s has added to the stress of daily living in rural areas. Recent studies focusing on individual rural areas report increases in depression and interpersonal problems, suicide, domestic violence, and alcohol abuse.

A faltering rural economy throughout the 1980s has both contributed to the need for mental health care and exacerbated problems of access to care. Many factors contribute to poor access in rural areas. These include a shortage of mental health care professionals, geography, stigma, and lack of financial resources. Rural inhabitants often do not seek help for mental health problems because it conflicts with traditional rural values such as a strong sense of independence and privacy. Rural America needs new strategies for outreach and treatment to counter these problems.

The 1990s do not promise better times. For example, the National AIDS Commission reported in August 1990 that the nation's rural communities are experiencing a drastic increase in AIDS. It cited a 35.4 percent increase in AIDS cases in one year in cities under 100,000 population, compared with a 4.6 percent increase in urban centers of 1 million people or more. For patients living in rural areas, AIDS brings worry of stigma as well as health and mental health concerns.

AccomplishmentsHearing On Mental Illness In Rural America

An ongoing mission of NIMH is to educate the public about mental illness and establish for the mental disorders a place in the nation's health agenda commensurate with their enormous social, psychological, and economic costs. As part of these efforts, the NIMH National Advisory Mental Health Council (NAMHC) and the National Mental Health Leadership Forum are sponsoring a series of hearings on mental illness in America. The first of these hearings, to explore mental illness in rural America, was held in Marshall, Minnesota, America's most rural congressional district, on April 12, 1990. The hearing involved a wide audience including health and mental health professionals, consumers, religious leaders, public officials, advocates and other members of the public.

Members of both the NAMHC and the Forum, as well as Dr. Frederick K. Goodwin, M.D., Administrator of ADAMHA and Dr. Lewis L. Judd, Director of NIMH heard testimony from numerous witnesses who spoke to the problems of rural life that contribute to mental health problems; the increase in rural suicide (especially in the young); the stigma of mental illness and its impact on access to care; and depression, a possible result of economic uncertainty and hardship in rural areas. Testimony provided at the hearing, and the views and opinions expressed at the open forum, focused on the unique mental health problems of rural America, barriers to appropriate care in these areas, and successful approaches that have been developed. Perhaps the most important information disseminated through the hearing were the success stories--experiences of individuals who have managed to overcome mental illness despite significant obstacles.

Mental Health Effects Of Rural Economic Hardship On Families

Early findings from an ongoing study at the Iowa State University are beginning to specify the links in the causal chain between economic hardship and psychological disorder. The study has identified several intermediary mechanisms that link economic hardship to aggressive behavior in adolescents. Economic pressure, stemming from low income, financial loss, and unstable work adversely affect parents' marital relationship. Marital discord contributes to increased negativity, irritability and hostility toward the adolescent, who in turn reacts aggressively with parents and peers. Specifying the particular causal method at work is valuable in identification of the most effective interventions.

NIMH-funded Rural Mental Health Demonstration Projects

Four rural mental health service demonstration projects in Iowa, Minnesota, Nebraska, and South Dakota were completed in FY 1990. An evaluation report, "Evaluation of the NIMH-Funded Rural Mental Health Demonstration Projects," provided valuable information which the Institute has disseminated to States, researchers, and mental health service facilities in rural areas.

Prior to these demonstrations, the States and Community Mental Health Centers (CMHC), in general, had not developed an aggressive response to the rural crisis. A major contributing factor was the crisis itself. There was no emergency funding priority and the crisis reduced the fiscal flexibility of the States. The demonstration grants provided funds at a critical time to communities that needed to test new approaches. The demonstrations included projects such as:

- o One CMHC placed paraprofessionals in the community to contact farm crisis victims that more conventional outreach efforts had missed. This emphasized the value of reaching out more aggressively and underscored the amount of effort required to help people in need.

- o A mental health counsellor was stationed at an Ag Action Center, Nebraska's "one-stop" centers for persons adversely affected by the rural crisis. The Ag Action Center proved to be an efficient location to reach rural clients in economic distress, as well as an effective base from which to develop stronger relationships with area schools.
- o A mental health counsellor was stationed part-time at a cluster of three physician's offices. This method reached poor, largely female rural clients.
- o Staffing a Recreational Vehicle with a mental health counsellor provided a mobile office to reach out to distant, poor communities. This approach dealt with accessibility issues and sufficient clients were accumulated to indefinitely support a part-time clinician in half of the communities the RV regularly visited. This approach was also more personal and less stigmatizing as the RV became a familiar fixture in the communities.
- o A demonstration referral program at one CMHC--emphasizing personal contact with referral sources, immediate service to referred clients, and immediate feedback to the referral source--dramatically increased referrals from physicians and schools.
- o A syndicated column on rural mental health in local papers proved to be a relatively inexpensive way to communicate basic mental health messages to scattered rural communities.
- o A multi-colored, glossy paper folder designed as an organizer displayed logos of the 13 area schools to which it was distributed. The "organizer" featured student artwork and creative writing about teenage concerns, including drinking and driving, the difficulties of getting parents to understand, dealing with feelings and the importance of friendship. This folder gave a large number of students access to a CMHC hotline number to call in a crisis.
- o A curriculum on rural change and rural mental health was developed to give Nebraska's teachers a resource they could use to talk about rural life and the social and emotional impacts of the crisis on students and their families. This gave mental health counselors something of value to distribute to teachers and school counsellors to establish and strengthen referral relationships.

Current Activities

The NIMH Office of Rural Mental Health Research

NIMH created an Office of Rural Mental Health Research in FY 1990 to provide leadership in this aspect of the Institute's mission. The office has developed a research announcement, "Research on Mental Disorders in Rural Populations," intended to stimulate

research on mental disorders as they occur in rural areas. The announcement encourages traditional research grant applications, small grants, First Independent Research Support and Transition (FIRST) Awards, research demonstration grants and rural research centers. Studies will increase understanding of the major mental health problems and risks associated with rural life, ways in which incidence and prevalence of mental disorders can be assessed and perhaps lowered, and ways in which mental health services can be made more accessible and delivered more effectively and economically to persons living in rural areas.

A second announcement, issued conjointly by the NIMH, the National Institute on Alcoholism and Alcohol Abuse (NIAAA), and the National Institute on Drug Abuse (NIDA), invited applications for research on prevalence of and services for mental disorders that co-occur with drug and/or alcohol abuse disorders among American Indians, Alaskan Natives, and Native Hawaiians.

Both announcements resulted in the submission of high quality applications that were funded by the NIMH with regularly appropriated funds and support made available for services research and data collection through a set aside in the alcohol, drug abuse, and mental health block grant.

All new Requests for Applications (RFAs) and Program Announcements (PAs) issued by NIMH research program divisions now incorporate the following notice to applicants: "Special encouragement is given to applicants for grants under this announcement to undertake studies on issues related to rural mental health or persons living in rural areas."

Two New Centers For Rural Mental Health Research

The University of Arkansas and Iowa State University successfully proposed research centers to provide an interdisciplinary environment to address major policy and services issues related to provision of rural mental health care. Using the rural diversity present in Arkansas as a natural laboratory, the University of Arkansas Center is emphasizing three areas of research: (1) assessment of rural child and adolescent mental health, (2) schizophrenia among rural residents, and (3) mental health care for rural elderly persons with cognitive impairment. The Iowa State Center will focus on the special role of families in rural society in providing support for physical and mental health maintenance, and for reducing the adverse behavioral and emotional consequences of economic stress.

Services Research Grants

In FY 1990, NIMH awarded the following grants for services research in largely rural areas:

- o The Adolescent Health Program of the University of Minnesota will study psychiatric disorders, substance abuse, and related service utilization in three widely separated, linguistically diverse, and largely rural American Indian

adolescent populations. The populations are the Navajo, seven Michigan tribes of the Bemidji area, and the Mississippi Band of Choctaw Indians.

- o Dr. Spero Manson of the University of Colorado received a research scientist award to develop and evaluate an innovative program aimed at improving treatment of depressive disorders among American Indian primary care patients. The field research is being conducted at an Indian Health Service outpatient clinic on the Navajo Indian reservation at Shiprock, New Mexico.
- o New NIMH-funded research at the University of Wisconsin is examining how burdens that rural families experience in caring for a severely mentally ill member are lessened or increased by family interactions with different types of county public mental health systems. This research is an outgrowth of a research center grant previously awarded to the University of Wisconsin for studies on the organization, financing, and delivery of mental health in nine rural Wisconsin counties.
- o Dr. J. Greer Sullivan of the RAND Corporation is examining use of public sector services by former inpatients at the Mississippi State Hospital who have been released into the community.
- o Dr. Frank deGruy of the University of South Alabama is conducting research on prevalence and treatment of somatization disorder in primary care patients.
- o Dr. Lee Badger of the University of Alabama School of Medicine at Tuscaloosa is examining reasons why primary care physicians so often overlook or misdiagnose depressive disorders.
- o A new NIMH grant to Dartmouth College is examining the cost effectiveness of two innovative approaches in a largely rural New England state to treatment of persons with dual diagnoses of severe mental illness and substance abuse disorder. The cost effectiveness of a conventional linkage model of case management within a comprehensive community support program is being compared with a model that integrates treatment for substance abuse and psychiatric disorders in an assertive case management approach.

The Future

As a result of the hearing on rural mental health held in Marshall, Minnesota and recent research findings, NIMH will introduce a new initiative to encourage applications for research demonstration funds to develop and test new methods of providing high quality care in rural areas. A pilot effort to expand mental health services by providing linkage between community-

based mental health facilities and local primary care centers was developed a decade ago offering one promising model for expanding mental health services for rural populations. Based on these findings, efforts to develop closer coordination of mental health and primary care services as well as other available community resources will be especially encouraged.

Office for Treatment Improvement

The Office for Treatment Improvement (OTI) was created in FY 1990 to provide a focal point within ADAMHA for improving the Nation's drug treatment system and has oversight of the Alcohol, Drug Abuse and Mental Health Services (ADMS) and the Mental Health Services for the Homeless (MHS) Block Grants. OTI provides grant funds to States and local treatment providers to assist them with the improvement of their drug treatment programs.

Treatment Programs for Critical Populations, directed at selected population groups that have an acute need for assistance in treating drug abuse, acknowledges that some populations operate mostly outside established delivery systems and are in need of special assistance to be able to receive treatment. The goal of these programs is to establish national prototypes for providing a continuum of comprehensive therapeutic services coupled with aftercare to improve treatment outcome. The homeless, rural populations, and patient subgroups with a high incidence of physical and mental illnesses or AIDS, in addition to substance abuse disorders, receive special attention under this program.

The Alcohol, Drug Abuse, and Mental Health Services (ADMS) Block Grant, administered by OTI, requires the States to use not less than 10 percent of the entire amount of the Block Grant to provide alcohol and drug abuse services designed for women and demonstration projects for the provision of residential treatment services to pregnant women. New services directed to women include attention to minorities, rural, criminal justice, indigent, and adolescent sub-populations.

HEALTH RESOURCES AND SERVICES ADMINISTRATION
Bureau of Health Care Delivery and Assistance

RURAL HEALTH

Within the Bureau of Health Care Delivery and Assistance (BHCD), primary care program activities in rural areas (including frontier) have as their objective the improvement of health care access and service delivery for medically underserved, disadvantaged populations. Rural health program activities have focused on the establishment and maintenance of organized systems of care through the integration or linkage of Federal, State and local resources. The retention and recruitment of qualified health manpower to maintain these systems has required the effective distribution of financial, medical and manpower resources of the community health center program, migrant health program, and the National Health Service Corps combined with the resources of other public and private entities.

At the end of Fiscal Year (FY) 1990 349 rural community and migrant health centers were serving approximately 2.8 million rural persons.

Black Lung Clinics

In FY 1990, Black Lung Clinic sites had sufficient capacity to serve an estimated 47,335 persons at 58 deliver sites through awards to 15 public and private non-profit entities. The aforementioned service capacity is expected to be maintained. In FY 1991, as in the past, the vast majority of the persons served will be residents of rural areas. These clinics are funded within other ongoing rural health centers, but can also be independent sites providing comprehensive health services in addition to black lung services. The Black Lung Clinics activities began in 1979 and are funded under the Federal Mine safety and Health Act of 1977.

HEALTH RESOURCES AND SERVICES ADMINISTRATION
Bureau of Health Professions

Rural Health

In FY 1990, most Area Health Education Center (AHEC) projects were involved either wholly or in part with rural health activities. Fourteen of the 19 AHEC projects received a total of \$4,849,729. The University of Washington received the largest award (\$2,565,749) for their AHEC rural health training involving 340,006 students, residents, and population of the multi-state area served by the AHEC. The clinical training and community education services emphasized through AHEC rural health activities are estimated to affect approximately 796,464 individuals, many of whom are underserved populations.

Eight of the projects funded under the new Health Education and Training Centers grant program are offering training for rural practice, and one grantee is developing initiatives for improving the availability, accessibility and quality of health care in rural areas along the U.S.-Mexico border. A total of \$752,657 was identified for these program development activities which are expected to impact the training and continuing medical education of approximately 1,403 individuals.

Under section 786(a) Family Medicine programs, 12 predoctoral and 26 graduate training programs indicated some rural health oriented training activities. Eight of the graduate training program grantees reporting rural health training experiences received a total of \$488,515 for their efforts. Rural initiatives include implementation of curricula covering patient care in community health center settings and the development of rural clinical rotations for residents. As reported by these grantees, graduate training will be enhanced for approximately 80 residents. The Family Medicine Faculty Development program at East Tennessee State University will provide experience in teaching rural health care for 52 faculty. At Michigan State University, the Family Medicine Departments grant is assisting with research conducted in rural settings.

Fourteen General Internal Medicine/General Pediatrics Residency programs offered rural health training experiences for 71 residents. One grantee identified funds in the amount of \$24,400 for this purpose.

Nursing programs support projects implementing outreach programs making basic advanced and continuing nurse education programs accessible to individuals and providing rural clinical practicums for nursing students. During FY 1990, the Advanced Nurse Education Program provided \$491,141 to four projects designed to prepare nurses at the graduate level to provide expert clinical care, particularly in acute care settings, and to prepare teachers and researchers in this important area. The Nurse Practitioner and Nurse Midwifery Program funded eight grants for \$1,052,355 which would prepare family nurse practitioners and nurse midwives specifically to work in rural areas of the

country. In 1990, the Nursing Special Projects program supported 16 projects for \$2,286,635 to increase the supply of adequately trained nursing personnel to meet the health needs of rural areas.

Approximately 907 students in 28 Physician Assistant Training programs benefited from the rural health activities supported by grants in the amount of \$134,449.

One Podiatric Primary Care Residency Training program grantee reported rural training emphasis for four residents. The University of Osteopathic Medicine and Health Sciences in Iowa received \$4,822 specifically for this purpose.

Eleven University-based grantees under Section 799A received awards totaling \$2,167,711 to support the interdisciplinary training of health professionals to recruit, prepare, and encourage them to enter into and/or remain in rural areas to provide health care services.

In FY 1989, \$1,360,000 was awarded to four geographically unique rural hospitals under the Ad Hoc Hospital Grants, P.L. 100-607. These funds were used for advancement of health care services and the enhancement of quality care. These same hospitals received \$1,343,000 in FY 1990.

Rural health care will be included in the training of nine fellows at two projects supported under the Geriatric Medicine and Dentistry Faculty Training program.

One AIDS Regional Education and Training Center projects have indicated training targeted toward rural health issues.

The Preventive Medicine Residency training program at the University of Arizona will provide rural health experience for one resident supported under its federal grant.

In FY 1989, an \$800,000 contract was awarded to study the supply of health professionals and whether such supply is adequate to meet the demands for health care services in rural communities. The contract work from this project forms the basis for a congressional report to be sent to the Congress in the Spring of 1991. An additional \$500,000 has been appropriated for FY 1991 to expand and continue the FY 1989 activities.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Office of Rural Health Policy

Rural Health

The Office of Rural Health Policy (ORHP) was established within the Health Resources and Services Administration in August 1987 and authorized by Congress in December 1987. The major responsibility of the Office is to work within the Department and with other Federal agencies, States, national associations, foundations, and private sector organizations to seek solutions to health care problems in rural communities.

During FY 1990, ORHP renewed grant awards to continue operations of its five Rural Health Research Centers. In September 1990, two additional centers were awarded research center grants. Funding for the seven centers in 1990 was approximately \$1.8 million. These Centers collect and analyze information, conduct applied research on rural health issues, and widely disseminate the results. The center directors met twice to collaborate and share information.

The National Advisory Committee on Rural Health held three meetings during the past year and submitted its annual report, with recommendations, to the Secretary in December. The purpose of this committee is to advise the Secretary on the priorities and strategies that should be considered for addressing the issues and unique problems related to providing and financing health care services in rural areas. Staff support to the committee was provided by ORHP. The Office continued to manage a 3-year demonstration grant to Texas Tech University that is establishing an interactive satellite-based video communications system and data exchange between teaching hospitals and rural physicians in West Texas.

In FY 1991, ORHP will continue to monitor performance of the seven Rural Health Research Centers. The Office will provide staff support to the Advisory Committee as well as continued management of the telecommunications demonstration. The National Rural Information Center Health Service (Information Clearinghouse) became fully operational in October 1990. ORHP will implement a matching grant program to States to support the establishment and operations of State Offices of Rural Health. Finally, ORHP will implement the Rural Health Outreach Program. The program will support projects that demonstrate new and innovative models of health care delivery in rural areas and will emphasize efforts to improve the integration and coordination of rural health services. Formal grant announcements for both the State Office and Rural Health Outreach Programs are expected in February 1991.

ORHP will also conduct a number of significant special projects to improve access to health care in rural areas.

NATIONAL INSTITUTES OF HEALTH

National Cancer Institute

RURAL HEALTH

Based on data from the Bureau of the Census, approximately 26 percent of the U.S. population resided in officially designated rural areas in 1980. In terms of the U.S. health care system, however, "rural" areas are also defined more specifically as "geographic areas characterized by low population density, which are remote from sophisticated specialty health care providers." Examples of these medically underserved areas can be found in Appalachia, Montana, Iowa, the northern portions of Minnesota and Wyoming, and Alaska.

Lack of access to state-of-the-art health care, exposure to specific environmental and occupational factors, and regional differences in lifestyle are considered major reasons for the often disproportionate rates of morbidity and mortality from cancer and other diseases in rural areas. This year, targeted research at the National Cancer Institute (NCI), the National Heart, Lung, and Blood Institute (NHLBI), the National Institute for Dental Research (NIDR), the National Institute for Environmental Health Sciences (NIEHS), the National Institute on Aging (NIA), the National Center for Nursing Research (NCNR), and the National Library of Medicine (NLM) sought to more accurately assess health problems in rural areas, identify their underlying causes, and develop programs to aggressively deal with them.

Pesticide Use May Increase Cancer Risk for Farmers

Approximately 65 percent of all pesticides used in these United States in 1976 were used by farmers; 25 percent may have been applied by commercial applicators who typically have considerable contact with pesticides. Heavy pesticide use may account for some excess risk of cancer among farmers. Evidence for this association comes mainly from occupational studies.

Intramural NCI scientists Drs. Sheila H. Zahm, Kenneth P. Cantor, and Aaron Blair; and contractors Drs. Dennis D. Weisenburger and Paula A. Babbitt at the University of Nebraska Medical Center in Omaha, and colleagues studied 201 white men in eastern Nebraska diagnosed with non-Hodgkin's lymphoma (NHL) between 1983 and 1986 to evaluate the role of the herbicide 2,4-dichlorophenoxyacetic acid (2,4-D) in the development of the disease.

The results showed that farmers who mixed or applied 2,4-D to their crops had a 50 percent increased risk of NHL compared with men from the general population who did not handle the pesticide. The risk of NHL also increased with frequency of

2,4-D use. Farmers who used the pesticides for 20 or more days per year had three times the risk of NHL than those non-farmers not exposed to the chemical. The association between NHL and 2,4-D use among Nebraska farmers is consistent with findings learned in a previous NCI study conducted in Kansas.

Intramural NCI scientists Linda M. Brown, Drs. Aaron Blair, and Kenneth Cantor; contractors Drs. Robert Gibson and Leonard M. Schuman at the University of Minnesota in Minneapolis; contractors Dr. George D. Everett at the Orlando Regional Medical Center in Florida; and contractors Drs. Leon F. Burmeister, Fred Dick, and Stephanie F. Van Lier at the University of Iowa in Iowa City studied 578 white men in Iowa and Minnesota diagnosed with leukemia between 1981 and 1984 to evaluate the role of fungicides, herbicides, and insecticides on the development of the disease.

The researchers found a slight increase of leukemia, especially chronic lymphocytic leukemia, among farmers. The risk was higher among farmers who used specific pesticides to eradicate insects on animals; the pesticides included the organophosphates crotoxyphos, dichlorvos, and famphur; the natural product pyrethrins; and the chlorinated hydrocarbon methoxychlor. Exposure to specific fungicides, herbicides (including 2,4-D), or crop insecticides did not increase the risk of leukemia. Additional information collected from 622 non-Hodgkin's lymphoma patients in the context of this study is now being analyzed.

Association of Drinking Water and Bladder Cancer Is Studied

Results from the National Bladder Cancer Study in 1987 suggested that certain drinking water contaminants are associated with an increased risk of developing bladder cancer. To evaluate the risk of bladder cancer related to drinking water quality in Iowa, NCI contractor Dr. Charles F. Lynch of the University of Iowa in Iowa City gathered data from 1,830 state residents (899 bladder cancer patients and 931 control persons) who responded to a mail questionnaire. Respondents were asked about the source of their drinking water, the amount and pattern of their drinking water consumption, and other bladder cancer risk factors (such as cigarette smoking and occupational carcinogens) to which they may have been exposed.

Data from this survey are being combined with information collected from 4,553 Iowa residents in an earlier evaluation of the association of drinking water contaminants and six cancer types (bladder, colon, rectum, pancreas, brain, and kidney). NCI intramural scientist Dr. Kenneth Cantor will conduct the analysis of the complete database.

Study of PBB and Cancer Mortality in Michigan Continues

Polybrominated biphenyls (PBBs), synthetic chemicals once used as flame retardants, have been shown to induce liver tumors, both benign and malignant, in rats and mice. No evidence of carcinogenicity has been shown so far in studies of humans exposed to PBBs.

In 1973, accidental contamination in Michigan of nearly 900,000 kilograms of cattle feed with PBBs provided scientists with an opportunity to study the long-term effects of widespread population exposure to the chemical. PBBs were passed on to many Michigan residents through consumption of contaminated dairy products and beef.

Since 1976, an ongoing, collaborative project of NCI, NIEHS, the Food and Drug Administration (FDA), and the Centers for Disease Control (CDC) has surveyed rural Michigan residents exposed to PBBs to evaluate the human health consequences of that exposure, including cancer mortality. The registry of 4,040 Michigan residents exposed to PBBs in 1973-74 is the largest and longest-running toxic chemical exposure study in the nation. The project coordinator is NCI contractor Lawrence F. Posey at CDC and the principal investigator is CDC subcontractor Dr. Harold E. B. Humphrey at the Michigan Department of Public Health.

This was the fourteenth year that the registry has been maintained. Research activities for the registry include annual interviews (by mail questionnaires, phone calls, or personal visits) to monitor personal data and health status; testing of registrants to check PBB levels in blood, breast milk, and fat. Plans call for monitoring to continue until 1995 when an entire generation will have been studied.

Cancer Prevention Program Started for Rural Energy Workers

As one element of a cooperative agreement between NCI and four cancer centers, the University of Texas M. D. Anderson Cancer Center in Houston began this year to develop, implement, and evaluate a comprehensive health promotion/cancer prevention program for diet and tobacco control specifically designed for rural, blue-collar energy transmission workers in the South. NCI grantee Dr. Michael P. Eriksen at M. D. Anderson is the principal investigator.

First-year activities were devoted to planning the intervention and assessment strategies for the overall program, in which five organizations (4 natural gas pipeline companies and the National Rural Electric Cooperative Association) and 40 worksites will participate. A pilot study of rural energy workers in Texas revealed that (1) they hold strong, possibly difficult to change, beliefs about their current health practices (primarily concerning diet and tobacco control); (2)

they have not been exposed as often to health promotion messages as white-collar workers; (3) they are interested in receiving health promotion information; and (4) 50 percent use tobacco products (30 percent cigarettes and 20 percent smokeless tobacco).

The pilot study also developed and refined the health assessment strategies to be used in the program including questionnaire content, survey methodology, and data analysis techniques. Response to the test survey was better than expected with more than 95 percent of the eligible workers participating.

With successful completion of the pilot study, plans are under way to begin implementing the main study. Nearly 10,000 workers will be assigned randomly to either of two study groups; half will receive the comprehensive intervention program and the other half will receive minimal intervention.

Program Started to Reduce Cervical Cancer in West Virginia

NCI grantee Dr. Kenneth J. Simon of the Mary Babb Randolph Cancer Center at West Virginia University in Morgantown and colleagues began a study aimed at reducing cervical cancer mortality rates in a nine-county rural, mountainous, and coal-mining region of southern West Virginia. The female population in this region has a relatively high cervical cancer mortality rate--the highest in the state and a major contributor to one of the nation's highest rates.

This year, the first phase of the study assessed the region's need for cervical cancer control efforts by interviewing women about their knowledge and/or utilization of cervical cancer screening, examining medical records, and targeting local health professionals and community leaders to support cervical cancer screening. Data obtained will be used in the study's second phase to develop an intervention program for the region.

Cancer Incidence and Mortality in Native Americans Studied

Native Americans (American Indians and Alaskan Natives) in rural areas have historically shown higher incidence and mortality rates for specific cancer types (cervical cancer, for example) as well as dramatically lower overall survival rates for all cancers when compared with whites. As part of an interagency agreement between NCI and the Indian Health Service (IHS), grantee Dr. William Freeman and colleagues at the IHS in Tucson, Arizona began a three-year study of cancer incidence and mortality in American Indian and Alaskan Native populations to determine the extent of these problems.

Data for this study are being drawn from several existing systems that collect data on health and health care events in

the two populations. This information has been collected for more than 15 years but has not been completely analyzed. In the first phase of the NCI/IHS project, a more definitive analysis of the data is under way to estimate cancer incidence and mortality rates by geographic location, tribal affiliation, and IHS patient service (catchment) area. The second phase of the project will attempt to identify the specific factors underlying the higher rates in cancer incidence and mortality.

Access of Rural Residents to Cancer Treatment Improved

The Community Clinical Oncology Program (CCOP), funded by NCI since 1983, is a major cancer control effort that links community-based physicians with clinical cooperative groups, cancer centers, and public health departments to facilitate their participation in NCI-approved treatment, cancer prevention initiatives, and cancer control clinical trials.

Fifty-one community programs (CCOPs) are currently funded through NCI cooperative agreements. This year, eighteen CCOPs served large rural populations, increasing the institute's outreach to these traditionally underserved areas and providing residents with access to state-of-the-art cancer treatment.

In addition, twelve programs with greater than 50 percent of new cancer patients from minority populations recently have been funded under a Minority-Based Community Clinical Oncology Program (MBCCOP) initiative. Four MBCCOPs serve rural populations in Texas, Virginia, and Puerto Rico.

National Heart, Lung, and Blood Institute

National Heart, Lung, and Blood Institute (NHLBI) research on rural health issues focuses on disorders of the heart, blood vessels, lungs, and blood that may be unique, more prevalent or more serious, or that may have different risk factors or interventions in rural populations.

Value of Education in Reducing Heart Disease and Stroke Confirmed

Begun in 1957, the NHLBI-sponsored Evans County (Georgia) Study continues to investigate cardiovascular health in a rural population cohort of 3,102 men and women, one-third of whom are Black. This year, NHLBI grantee Dr. Curtis G. Hames reported a clear association between educational programs and a reduction in both the prevalence of hypertension and mortality in referred care patients. The study also found that (1) smoking and coffee drinking have an additive effect on storage of lipids (fat and fat-like substances) in the body; (2) hypertension in Blacks appears to have a different origin and progression than in whites; and (3) one-third of the over-40 Blacks in the region of Nigeria that was the area of ancestral origin for many of the Georgia Blacks were hypertensive.

American Indian Groups Show Varied Heart Disease Rates and Risks

Begun in 1988, the NHLBI-supported Strong Heart Study seeks to estimate the morbidity and mortality rates from cardiovascular disease among three geographically diverse American Indian groups, in South Dakota, Oklahoma, and Arizona. Most of the Indians studied live on rural reservations.

Initial results from 2,278 of the projected 4,500 participants (men and women ages 45 to 74) in the study confirmed that the three groups have significant differences in cardiovascular risk factors and disease prevalence. Overall, blood pressure appears to be lower than that of the general U.S. population (it is lowest in the South Dakota group). Smoking rates vary significantly among the sites. Total and low-density lipoprotein (LDL) cholesterol levels differ sharply between groups as well as overall; these levels appear to be lower than those found in the general U.S. population. Obesity among the American Indians studied does not appear to be associated with higher blood pressure and cholesterol levels, as it is in the white population. An evaluation of electrocardiogram readings from the three groups shows a two-fold difference between the highest prevalence rate of cardiovascular disease (among the Indians in South Dakota) and the lowest rate (among the Indians in Arizona).

National Institute of Environmental Health Sciences

Research supported by the National Institute of Environmental Health Sciences (NIEHS) on rural health includes studies of the effects of agricultural chemicals (pesticides, herbicides, and fertilizers) and other groundwater contaminants on biological systems and the mechanisms by which such effects occur.

Researcher Investigates Human Metabolism of Insecticides

NIEHS grantee Dr. Clement E. Furlong at the University of Washington in Seattle is studying genetic variability in the body's metabolism of organophosphates and organophosphonates, chemicals commonly used in insecticides. His results suggest that a human blood component, paraoxonase, is the major enzyme involved in the metabolism of these compounds. He has shown that the enzyme's polymorphism (existence in multiple forms) and its variable concentrations in the blood help determine an individual's susceptibility to health effects from organophosphates and organophosphonates. These factors may be important for assessing the likelihood of health problems in persons exposed to the chemicals.

Animal Studies May Detect Health Effects of Chemicals

Lindane (gamma-hexachloro-cyclohexane) is a commonly used insecticide that may be widely distributed in low concentrations throughout the human food supply. NIEHS intramural scientist Dr. Hue-Hua L. Hong has determined that lindane is toxic to mouse bone marrow and that short-term exposure to the chemical can cause continuing damage to developing bone marrow cells. Dr. Hong also is investigating the possible toxic effects on mouse bone marrow of groundwater contaminated by pesticide and fertilizer mixtures.

In other research, NIEHS intramural scientist Dr. Richard Irwin and contractor Dr. Richard Prejean at the Southern Research Institute in Birmingham, Alabama are evaluating in rats the long-term health effects of contaminated drinking water. The animals are receiving drinking water that contains 20 chemicals to simulate groundwater contamination by pesticides and nitrates. Various analyses are being performed to discover any adverse changes caused by agricultural chemicals. This work will help determine if groundwater contamination poses a significant health risk to people in rural areas.

Agricultural Health Research Center Established in Iowa

Recently, NIEHS established a Center of Excellence at the University of Iowa in Ames for coordinating epidemiologic research on human health risks from exposure to agricultural chemicals. NIEHS grantee Dr. James Merchant is the center's

director.

The Center also will support researchers conducting studies on the health effects of a number of specific agricultural chemical exposures. NIEHS grantee Dr. David Schwartz at the University of Iowa is investigating the biologic relationship between exposure to mixed grain dust and the development of respiratory disorders such as bronchitis and airflow obstruction. The health consequences of such exposure are substantial; at least 30 percent of the more than 500,000 workers annually exposed to grain dust show symptoms of bronchitis.

National Institute on Aging

The National Institute on Aging (NIA) is especially interested in the special problems that older people living in rural communities may have in accessing health care services.

Unanticipated Moves Associated with Poor Health

Moving from one's home can be a stressful experience. How this experience differs for older people living in rural communities is the area of interest for NIA contractors Drs. Patricia L. Colsher and Robert B. Wallace at the University of Iowa in Iowa City. They examined how relocation in a rural community affects an individual's mental and physical health and social status. Participants in this study were drawn from the Iowa 65+ Rural Health Study, one of four NIA-funded Established Populations for Epidemiologic Studies of the Elderly (EPSE). The Iowa participants, all age 65 or older, originally resided in two rural Iowa counties. The respondents, 1,094 men and 1,883 women, were interviewed and asked about their medical history, physical and mental abilities, and friendships, as well as their health and emotions.

At the beginning of the study, all participants were asked about their plans to move within the next few years. They also were asked if a physician had diagnosed any major illnesses within the past year. The survey also reported on their participation in clubs, fraternal organizations, and religious groups. During follow-up, the participants were classified as having moved, and whether they made a non-institutional move or were institutionalized.

Drs. Colsher and Wallace administered a test based on an index of depression symptoms to determine if there was an association between the participants' willingness to move and their mental and physical health. They found that participants who did not plan for a move had the poorest physical health and the highest number of doctor visits. Further, these participants also rated high on the index of depression symptoms and low on levels of life satisfaction.

The researchers observed that the impetus for moving was generally associated with the death of a spouse or the marriage of a child--conditions that may cause people to feel more dependent. According to Drs. Colsher and Wallace, a self-motivated decision to move seems related to the participants' ability to engage in social activities with civic groups and fraternal organizations. A thorough investigation of the health and socioeconomic circumstances of older rural residents implies the need to study older individuals in the context of their social environment.

National Center for Nursing Research

National Center for Nursing Research (NCNR) studies on rural health focus on access to health care, nursing care, and health care needs of certain populations, including adolescents and minorities.

Sexual Activity Studied Among Rural Eighth Graders

Much of the research on adolescent sexual behavior has focused on urban areas and relatively little is known about early sexual activity in adolescents who live in rural areas. NCNR grantee Dr. Cheryl S. Alexander and colleagues at The Johns Hopkins University School of Public Health and Hygiene in Baltimore, surveyed 758 eighth-grade students from three rural Maryland counties about their sexual experience, drug and alcohol use, cigarette smoking, and other health-risk behaviors. The average age of the students was 13. About 40 percent of the students were Black.

The investigators found that 61 percent of males and 47 percent of females had had sexual intercourse. Among all Black students, the figure was 77 percent; among all white students, it was 40 percent.

Cigarette smoking and use of alcohol or certain other drugs were associated with a greater likelihood of sexual activity, but the association varied among subgroups. Cigarette smoking was related to an increased rate of sexual activity among only white females in this study, while alcohol use was associated with sexual experience among Black females and white males. White students who used drugs other than marijuana or alcohol had five to nine times higher rates of sexual activity, but there was no significantly increased rate among Black students. White and Black males who lived in a town were more likely to have had sexual intercourse than were those who lived in the country, but this did not apply to females of either race. Frequent cruising in cars with no particular destination increased the likelihood of intercourse for all white students and for Black males, but not for Black females.

Ten percent of white students reported having used drugs such as tranquilizers, amphetamines, or cocaine, compared with five percent of Black students. Black eighth-graders are likely to be older than white eighth-graders, more likely to live in towns, and more often came from a single-parent home.

A better understanding of the reasons for early sexual experience by race and gender can help nurses, counselors, teachers, and parents develop better programs to help avoid the risks of pregnancy and sexually transmitted diseases related to such experience. Dr. Alexander and colleagues are continuing to survey the same group of students through the twelfth grade to gain further information about health-risk behaviors in this population.

National Library of Medicine

In 1988 the Senate Committee on Appropriations requested that the National Library of Medicine "develop an active outreach program to disperse [the latest scientific and technical findings] to rural and remote health care professionals, and devise a method of notifying these professionals of the availability of up-to-date information." An NLM Panel on Outreach, chaired by Dr. Michael DeBakey, in 1989 outlined steps to implement the Senate Committee's mandate, looking eventually to put NLM's vast store of knowledge into the hands of every health practitioner in the country. This year, the Library used approximately \$3.8 million provided by Congress for "outreach enhancement" of a number of NLM ongoing programs, with special emphasis on the needs of health professionals in rural and other underserved areas.

Outreach Funds Enhance Regional Medical Library Contracts

Through the addition of special enhancements to NLM's Regional Medical Library contracts (\$1.4 million), the Library has funded demonstration projects in 12 states to test ways to increase awareness of NLM's information services. Examples include the following: 1) a project in the Pacific Northwest has helped introduce GRATEFUL MED--NLM's inexpensive software package for linking its databases to libraries and individuals with personal computers--to more than 260 hospital administrators and medical staff throughout the region; 2) a pilot project in Mississippi, where there is only one major university medical library, is creating an electronic network to help rural health professionals obtain reference assistance, request books and journal articles, and conduct GRATEFUL MED searches; and 3) an inner-city section of New York City and a six-county rural area in the southern tier of New York State are targeted for studies to determine the special information needs of health professionals serving these areas, and for workshops to teach them about existing resources. Similar projects are under way in Iowa, North Dakota, South Dakota, Oklahoma, and West Virginia.

Funds Strengthen Hospital Access to Information Sources

A total of \$1.2 million in grant funds has been allocated to help improve access of community-based hospital libraries to national sources of information. As an example, "Information Access Grants" have helped libraries in Eastern Kentucky to introduce GRATEFUL MED to a largely rural population of health professionals. Outreach funds in this area also are allowing NLM to augment its IAIMS (Integrated Academic Information Management Systems) program. The IAIMS program at the American College of Obstetricians and Gynecologists, for example, makes information accessible to practitioners throughout the United States.

SEXUALLY TRANSMITTED DISEASES
Obligations

	<u>1988</u>	<u>1989</u>	<u>1990</u>	<u>1991</u> <u>Estimate</u>	<u>1992</u> <u>Estimate</u>
Public Health Service:					
<u>National Institutes</u> <u>of Health:</u>					
National Institute of Allergy and Infectious Diseases.....	\$34,224,000	\$39,828,000	\$38,849,000	\$42,157,000	\$45,760,000
National Cancer Institute	12,050,000	13,024,000	17,700,000	18,725,000	19,445,000
National Heart, Lung and Blood Institute.....	---	281,000	293,000	310,000	335,000
National Institute of Dental Research.....	---	205,000	970,000	1,060,000	1,136,000
National Institute of Neurological Disorders and Stroke.....	206,000	225,000	416,000	437,000	467,000
National Institute of Child Health and Human Development.....	6,424,000	5,642,000	5,132,000	5,600,000	6,000,000
National Eye Institute.	---	---	1,059,000	1,101,000	1,145,000
National Center for Research Resources 1/.....	570,000	738,000	1,382,000	1,371,000	1,312,000
National Center for Nursing Research.....	681,000	755,000	2,603,000	3,207,000	3,436,000
Office of the Director 2/ Total, NIH.....	78,000	---	195,000	200,000	200,000
	54,233,000	60,698,000	68,599,000	74,168,000	79,236,000
Centers for Disease Control.....	65,161,000	78,700,000	81,316,000	84,783,000	89,548,000
TOTAL PHS.....	119,394,000	139,398,000	149,905,000	158,951,000	168,784,000

1/ This includes RCMI awards. Prior to FY 89, RCMI's were shown in OD.

2/ This includes AREA awards for FY 1988 - 1992, and RCMI awards for FY 1988.

NATIONAL INSTITUTES OF HEALTH

National Institute of Allergy and Infectious Diseases

SEXUALLY TRANSMITTED DISEASES

Sexually transmitted diseases (STDs) are of compelling importance worldwide, in large measure because of their potentially devastating impact on women and infants and because of their relationship to acquired immunodeficiency syndrome (AIDS). Each year, more than 13 million persons in the United States acquire an infectious disease other than AIDS as a result of sexual contact. The costs, both in terms of human suffering and financial burden on the health care system, are enormous and increasing because of the recent dramatic rise in the incidence of certain STDs in the United States.

For many women, the effects of STDs can be serious and, in some cases, irreversible. They include infertility, potentially fatal ectopic (tubal) pregnancy, cervical cancer, and poor pregnancy outcome (premature delivery, miscarriage, and neonatal death). Babies infected before or at birth can be severely affected by STDs such as syphilis, herpes, gonorrhea, chlamydial infection and genital warts.

The National Institute of Allergy and Infectious Diseases (NIAID) supports basic and clinical research on STDs. Current research priorities and initiatives focus on the sequelae of STDs in women, behavioral research, vaccine development, human papillomaviruses or HPVs (which cause genital warts) and their association with genital cancers, genital ulcer disease, and the development of rapid, inexpensive diagnostic tests. NIAID's intramural scientists conduct basic and clinical studies on STDs, including research aimed at developing vaccines to prevent chlamydial infections, gonorrhea, and genital herpes.

Other components of the National Institutes of Health that support research on STDs include the the National Cancer Institute (NCI), the National Heart, Lung, and Blood Institute, the National Institute of Dental Research, the National Institute of Neurological Disorders and Stroke, the National Institute of Child Health and Human Development (NICHD), the National Eye Institute, the National Center for Research Resources, and the National Center for Nursing Research.

NIAID conducts and supports basic research necessary for the development of vaccines to prevent STDs, particularly gonorrhea, chlamydial infections, syphilis, and genital herpes. Two candidate vaccines for herpes are in phase I clinical trials, which will determine whether the vaccines are safe, what the appropriate dose should be, and whether they stimulate the immune system to produce antibodies. If these trials are successful, expanded testing will be carried out within the next few years.

Because of the interplay between behavioral and biomedical risk factors for STDs, NIAID is developing a program of intervention-oriented behavioral research for the prevention and control of STDs. NIAID co-funds research in this area with NICHD and the National Institute of Mental Health.

Experimental Chlamydia Vaccine Tested in Animals

In the United States each year, an estimated 4 million men and women are infected with Chlamydia trachomatis, the leading bacterial cause of STDs. In men, these bacteria can cause inflammation of the urethra. Untreated or inadequately treated chlamydial infections in women can result in pelvic inflammatory disease (PID). PID resulting from chlamydial infection is three times more likely to lead to infertility than when it results from gonorrhea. There is also evidence that chlamydial infections during pregnancy can result in fetal death, low-birth-weight infants, and congenital infection.

Intramural scientist Dr. Harlan Caldwell and colleagues at NIAID's Rocky Mountain Laboratories (RML) in Hamilton, Montana, are continuing to study the role of the major outer membrane protein (MOMP) of C. trachomatis in the attachment of the bacteria to host cells, which is the first step in the infectious process. These studies confirmed that the MOMP promotes nonspecific attachment to the host cells, and when the chlamydiae are denatured physically in ways that result in changes in the conformation of the MOMP, the chlamydiae fail to attach to host cells.

In related research, Dr. Caldwell and his colleagues have used recombinant DNA techniques to construct a vaccine using vaccinia virus (the cowpox virus used in the smallpox vaccine) and the MOMP gene fragments that are involved in attachment. This experimental vaccine has elicited antibodies to C. trachomatis in mice; future studies in animal models will assess whether this vaccine protects against chlamydial infection.

Ways Found In Which Gonococcus Evades Immune System

Of the estimated 2 million new cases of gonorrhea diagnosed in the United States each year, about one-fourth occur among teenagers. As with chlamydial infection, the impact of gonococcal infection is most severe for women and children. It can result in PID, infertility and ectopic pregnancy in women and eye infections in newborn infants.

NIAID grantee Dr. Lee Wetzler and colleagues at Rockefeller University in New York City are studying the molecular mechanisms involved in an enzymatic alteration of lipopolysaccharide, a surface protein of the gonococcus. This defense mechanism of the bacteria prevents the immune system from recognizing and attacking it, even when antibodies to the gonococcus are present.

NIAID grantees Drs. Milan Blake at Rockefeller University and Peter Rice at Boston University in Massachusetts have described another way in which the gonococcus evades the immune defenses. They found that human antibodies to a gonococcal outer membrane protein actually block the killing of gonococci by normal human serum. Why serum from some individuals who have never had gonorrhea have this innate bactericidal activity is not well understood. Based on this work, NIAID grantee Dr. Emil Gotschlich and colleagues, also at Rockefeller University, are trying to characterize two other proteins that probably also elicit blocking antibodies: a meningococcal outer membrane protein, which is identical to the gonococcal outer membrane protein, and a protein of the bacterium Escherichia coli found in healthy human intestines, which is somewhat similar. Gonococcal and meningococcal mutants have been made that lack these proteins, and these strains may be important for vaccine development.

Douching Found Associated With PID

Pelvic inflammatory disease (infection of the upper female reproductive tract) is a serious condition that can lead to infertility, tubal pregnancy, and chronic pelvic pain. Untreated or delayed treatment of chlamydial infections, gonorrhea, and other bacterial vaginal infections can result in PID. Between 750,000 and 1 million American women are diagnosed with PID each year. Of the 10 to 15 percent of American women of reproductive age who have had PID, one-fourth suffer from tubal scarring and its irreversible consequences. About 70 percent of those women who develop PID are younger than age 25, and about 75 percent have not yet had a child.

Subclinical PID (disease without symptoms) is thought to be responsible for much of the PID-related infertility. NIAID grantees Dr. Dorothy Patton and colleagues at the University of Washington in Seattle found that among infertile women, those who had never experienced symptoms of upper genital tract infection had fallopian tube damage similar in degree and type to those with a history of symptomatic PID. This finding points to the urgent need to develop better methods of diagnosis for subclinical PID.

In another study on PID by NIAID- and NCI-supported researchers at the University of Washington in Seattle, led by NIAID grantee Dr. King Holmes, vaginal douching was found to be associated with an increased risk of PID. Women who douched once or twice a month were more than three times as likely to have PID as those who reported douching less than once a month. The investigators concluded that although further studies are needed to determine whether douching is actually a risk factor for PID, women should be advised that douching may be harmful.

Progress Made in Preventing and Treating Genital Herpes

Herpes simplex virus type 2 (HSV-2), the primary cause of genital herpes, is one of several viruses associated with herpes infections. (HSV-1 usually causes cold sores.) Persons can be infected and not experience any symptoms of genital herpes, which makes it difficult to know how many people have the disease and to control its transmission. An estimated 40 to 60 million persons in the United States have genital herpes, and about 500,000 new cases occur each year.

After initial infection occurs, HSV enters nerve cells where it remains dormant. Periodically, it can reactivate, traveling along the nerve to the skin, where it may produce ulcers. The lesions are often painful, and although an antiviral drug (acyclovir) is now available to treat the symptoms, there is no cure for herpes. Persons with damaged immune systems have more severe and more frequent episodes of herpes infection. About 100 newborn infants per year are infected with HSV before or during birth. Fifty percent of these babies die or suffer permanent neurologic impairment. In people exposed to the human immunodeficiency virus (HIV), which causes AIDS, genital herpes increases the risk of HIV infection at least two- to fourfold.

NIAID grantees are studying mechanisms of latency and reactivation of HSV to aid in developing new treatments. Using a mouse model and a mutant strain of HSV-1, Drs. Nigel Fraser and Jordan Spivack at the Wistar Institute in Philadelphia, Pennsylvania, investigated how the virus initially establishes infection in nerve cells after it enters the body. Their results suggest that establishment of a latent infection may not require initial virus replication in the nerve cells, as previously believed. If confirmed in other models, this finding will have important implications for the prevention and treatment of herpes.

Based on the knowledge that HSV is transported via the sensory nerves, NIAID grantee Dr. Lawrence Stanberry of the University of Cincinnati College of Medicine in Ohio has been studying a compound that interferes with sensory nerve function as a possible treatment for HSV genital infection. This compound, injections of capsaicin, is the principal irritant component of hot peppers. In guinea pigs treated with injections of capsaicin before intravaginal inoculation of HSV-2, genital herpes lesions were prevented or reduced in number although replication of the virus in the vagina and neural tissues was not altered. Capsaicin treatment of animals with latent infections reduced both spontaneous and ultraviolet radiation-induced recurrent herpes. Additional studies are needed to determine how capsaicin works and whether other agents that act on nerves may be useful in developing new strategies to control genital herpes.

Scientists Investigate Better Diagnosis and Treatment of Trichomoniasis

Vaginal infections are the most common reason why American women of reproductive age seek medical care. The protozoan parasite Trichomonas vaginalis causes a vaginal infection known as trichomoniasis, which is one of the most common STDs. Diagnosis of trichomoniasis in men and in some women is difficult, and treatment is hindered by the fact that the organisms can be resistant to the standard treatment with the drug metronidazole.

For infection to occur, the parasite must be in direct contact with epithelial (skin) cells. NIAID grantees Drs. Rosanna Arroyo and John Alderete at the University of Texas Health Science Center in San Antonio have studied the role of cell surface proteins and certain enzymes, known as cysteine proteinases, in adherence of the parasite to epithelial cells. Treatment of the T. vaginalis organisms with proteinase inhibitors prevented the trichomonads from killing host cells, a finding with important implications for the development of new treatments for trichomoniasis.

NIAID grantees at the University of Washington in Seattle studied the clinical symptoms associated with trichomoniasis. Dr. John Kreiger and colleagues found that colpitis macularis (strawberry--or red--cervix) was the most specific clinical finding and was most predictive for a diagnosis of trichomoniasis, although this symptom was observed in fewer than half of the women with trichomoniasis. Clinical symptoms were not found to be associated with experimental characteristics of the organisms, pointing to a need for additional study on the mechanisms of trichomonad virulence, the natural history of infection, and the role of host factors.

NIAID epidemiologist Dr. Mary Frances Cotch reported that women infected with T. vaginalis have an increased risk of having preterm deliveries and low-birth-weight babies. This finding resulted from a study--also supported by NICHD--of 12,281 women who had vaginal cultures taken at the end of the second trimester of pregnancy. Preterm delivery occurred in 15.1 percent of the infected women compared with 11.1 percent of uninfected women; low-birth-weight infants were born to 11.7 percent of infected mothers compared with 7.3 percent of uninfected mothers. The increased risk was evident even after taking into account other potential risk factors for adverse pregnancy outcome.

STDs Found Linked To HIV Infection

It is increasingly clear that STDs and infection with HIV, the cause of AIDS, are linked in a number of important ways. In addition to being transmitted primarily through sexual contact, STDs and HIV share common behavioral and biological risk factors. There is a well-documented increase in HIV transmission in the

presence of genital ulcer diseases such as chancroid, syphilis, and genital herpes. A 1989 World Health Organization consensus statement concluded that "the evidence for genital ulcer disease as a risk factor for HIV transmission is sufficiently strong that intervention [in genital ulcer disease] may contribute to prevention of sexual transmission of HIV." Recent studies also implicate other, more common STDs in HIV transmission, such as chlamydial infection, gonorrhea, trichomoniasis, and genital warts.

Furthermore, the course of STDs may be altered in the presence of HIV, leading to more frequent and severe recurrences of genital herpes and genital warts, increased neurologic involvement in syphilis, and increased premalignant cervical lesions associated with HPVs.

National Cancer Institute

During 1990, National Cancer Institute (NCI) scientists and grantees reported new findings on the association between certain sexually transmitted human viruses and the development of some cancers. These viruses include HPVs, which have been associated with the development of cervical and anogenital cancers; human T-cell lymphotropic virus type 1 (HTLV-1), linked with adult T-cell leukemia-lymphoma (ATL); and HTLV-2, associated with hairy-cell leukemia.

Role of HPVs in Increasing Cancer Risks Explored

At least 60 different varieties of HPVs have been identified. Some, like the ones that cause common skin warts, are not sexually transmitted. However, about 20 types of HPVs can be spread through sexual contact, and several of these, particularly HPV-16 and HPV-18, may play a role in the development of anogenital cancers including cervical and anal cancers.

Each year, an estimated 13,500 American women are diagnosed with cervical cancer, and 6,000 women die of the disease. Of an estimated 2,300 new cases of anal cancer that occur each year, 1,450 are in women and 850 are in men. About 800 deaths occur annually from anal cancer, distributed equally among men and women.

In a large multicenter study, NCI intramural scientist Dr. Louise Brinton, in collaboration with Dr. William Reeves of the Gorgas Memorial Laboratory in Panama, evaluated the role of HPV-16 and HPV-18 in the development of cervical cancer among 2,300 women in Latin America. In this study, women who were infected with either virus had a fivefold increase in risk of cervical cancer compared with women not infected with HPV. Although in this study HSV-2 was not a risk factor in the absence of HPV infection, the two viruses acted synergistically. Women infected with both viruses had nine times the risk of developing cervical cancer compared to noninfected women.

In an effort to understand how HPVs transform normal cells to cancerous ones, intramural researcher Dr. Peter Howley and NCI grantee Dr. Arnold Levine of Princeton University in New Jersey, have examined cellular events that may be triggered by one of the genes--known as E6--of HPV-16 and HPV-18. They found that a protein produced by the E-6 gene binds to a cellular protein, p53, which normally inhibits cancer cell growth. By forming a complex with the p53 protein, the E6 protein may allow normal cells to grow out of control.

Moreover, the scientists found that the binding efficiency between the two proteins was related to the HPV strain from which the E6 protein came. E6 from "low-risk" HPVs (types 6,11), which are generally associated with genital warts, did not bind to p53,

whereas "high-risk" HPVs (types 16, 18), which are associated with anogenital cancers, were effective in binding to p53 and thus blocking its activity.

Last year, Dr. Peter Howley, in collaboration with NCI grantees Drs. Ed Harlow and Nicholas Dyson at Cold Spring Harbor Laboratory in New York, found that the protein product of another HPV gene, E7, binds to the protein product of the gene linked to retinoblastoma (RB), a cancer of the eye. The researchers believe that this binding may inactivate the RB protein, thus allowing normal cells to grow out of control. This year, Howley's team and another NCI intramural researcher, Dr. Douglas Lowy, found that the E7 protein from HPV-16 and HPV-18 binds to the RB protein more efficiently than does the E7 protein from HPV-6 and HPV-11. This finding suggests that the efficiency with which these viral proteins bind to proteins that suppress cancer correlates with cancer risk and may provide clues to understanding how normal cells turn cancerous.

Risk Factors and Genetic Mechanisms of HTLV Elucidated

HTLV-1 and HTLV-2 can be transmitted by blood, in utero, through sexual contact or breast milk. In the United States, HTLV-1 primarily affects Blacks, and recent findings suggest that HTLV-2 is particularly prevalent among intravenous drug users.

NCI grantee Dr. Nancy Mueller of Harvard University in Boston, Massachusetts, and her colleagues evaluated the role of p42, a gene product of HTLV-1, in transforming into malignant cells the T cells of patients with ATL, a rare outcome of HTLV-1 infection. Dr. Mueller compared detection of antibody to the p42 protein in blood samples from HTLV-1 carriers with those from ATL patients in southwest Japan. The ATL patients were three times more likely to lack antibody to p42 than were HTLV-1 carriers. The scientists also tested the samples for antibody to p24, the HTLV-1 core protein that elicits the strongest immune response. After clinical diagnosis, the most sensitive blood marker for ATL was lack of antibody to p42, particularly among patients with antibody to p24. Based on these findings, the scientists now plan to examine whether they can use this altered response--lack of antibody to p42--as a predictor of either risk for, or progression of, ATL.

NCI epidemiologists Drs. Edward Murphy and William Blattner, in collaboration with researchers in Frederick, Maryland, and in Jamaica, evaluated sexual transmission of HTLV-1 among 2,000 patients who attended STD clinics in Jamaica. After the data were adjusted for age, the researchers found that the prevalence of HTLV-1 infection was higher among the women in this study than among female food handlers in another study (who were believed to be representative of the general population). The scientists found that a relatively higher number of lifetime sexual partners and a history of syphilis and/or positive syphilis blood test correlated with detection of antibody to HTLV-1 in these women.

NCI scientist Dr. Stephan Wiktor identified a reservoir of HTLV-2 infection among Black drug abusers. Molecular analysis of a 1985 blood survey of intravenous drug abusers in New Orleans had shown a high rate of HTLV-1 or HTLV-2 antibodies among Blacks. Contrary to expectation, Dr. Wiktor found that the majority of the Black drug abusers were infected with HTLV-2 rather than HTLV-1.

National Institute of Child Health and Human Development

The National Institute of Child Health and Human Development (NICHD) supports a research program examining the role of contraceptives in preventing STDs.

Oral Contraceptives May Increase Risk of Certain STDs

It has been previously publicized that oral contraceptive users have a lower risk of hospitalization for severe PID, particularly gonococcal PID. A new study conducted under contract for NICHD by Dr. Daniel Cramer at Harvard University determined that some types of oral contraceptives may have increased the risk of infertility among 283 infertile women who had never been pregnant and who had tubal adhesions or blockages compared with almost 3000 controls. This increased risk appeared to be associated with high-estrogen content oral contraceptives, which had been used in the past. Overall, the researchers found that today's oral contraceptives appear to have no effect on the risk of PID.

Another study, headed by contractor Dr. William Louv at the University of Alabama in Birmingham, evaluated the role of oral contraceptives on cervical colonization with STD pathogens. This study confirmed previous observations that oral contraceptive users are more likely to have subclinical chlamydial infections than nonusers. Users of oral contraceptives may also be more likely to harbor gonococci. Despite the fact that the pill reduces the severity of gonorrhea infections, Dr. Louv recommends that oral contraceptive users be routinely screened for gonococci and other common STD pathogens when they renew their prescriptions.

Barrier Methods Can Prevent STDs

Although pregnancy rates for barrier contraceptive users are higher than those for pill and intrauterine device (IUD) users, the acceleration in the epidemic of STDs has tilted the risk/benefit ratio toward the use of barrier methods. Combinations of oral contraceptives and barriers may be warranted for women who are at high risk for both pregnancy and STDs.

An extensive effort is under way as part of the NICHD research program to quantify the degree to which condoms and spermicides--alone and in combination--reduce the risk of STDs.

Laboratory experiments directed by NICHD contractor Dr. Roger Detels at the University of California at Los Angeles evaluated the effectiveness of condoms as viral shields. Using the electron microscope, Dr. Detels found that latex does not have holes or pores that would allow for the passage of viral particles of any size.

Other studies conducted by Dr. Detels have evaluated the effectiveness of spermicides used in conjunction with condoms. The use of spermicides with condoms reduced the amount of viable virus leaking from intentionally damaged condoms, supporting the hypothesis that spermicides used in conjunction with condoms offer additional protection. Laboratory experiments were also conducted on six spermicides to study their comparative effectiveness in inhibiting nine of the organisms that cause STDs. The spermicides included two, nonoxynol-9 and octoxynol, that are marketed in the United States. The results suggest that all spermicides are effective against some of the common STD organisms. Extracellular pathogens such as bacteria appeared to be more sensitive to the inhibitory effects of spermicidal agents than intracellular agents, particularly viruses. Octoxynol and benzalkonium chloride appeared to have the best overall effectiveness against a spectrum of STD agents.

Research Outlook

STDs are among the many diseases that disproportionately affect women, children, and minority populations. Researchers are actively pursuing basic and clinical investigations on the prevention and treatment of STDs and their complications. These efforts include the development and testing of vaccines, improved methods of diagnosis, better treatments, and behavioral methods of intervention. Progress in STD research offers the prospect of a brighter future for many among our population. Given the prevalence of STDs in some populations and the role of STDs in the transmission of HIV, prevention and control of STDs is an essential component of controlling the HIV pandemic.

Centers for Disease Control
Center for Prevention Services
Sexually Transmitted Disease

I. INTRODUCTION

Sexually transmitted diseases continue as one of the Nation's most serious public health problems. Not only is HIV infection the most devastating public health problem of this century, but also infectious syphilis has continued increases unprecedented since the advent of penicillin therapy; resistant gonococcal infection is steadily increasing; chlamydial infections account for twice as many cases as gonorrhea; studies of human papillomavirus associate it with the development of cervical dysplasia; and trichomoniasis and other vaginal infections are being recognized as potentially major contributors to premature birth.

Achieving the Year 2000 objectives to reduce morbidity and mortality from STD by preventing cases and complications requires a partnership effort and a sharing of responsibility by Federal, State and local governments, private medicine, and voluntary community-based organizations. The Federal Government supports this partnership and meets its share of this responsibility through national leadership activities which include technical assistance in planning, developing and implementing control approaches; technical consultation in reviewing and monitoring control efforts; developing clinical standards and management systems; training; and providing epidemic assistance, disease information and prevention strategies. Direct Federal financial assistance is a critical component of the partnership and supports disease monitoring, screening, sex partner notification services, health education for risk reduction, and other outreach efforts in all States. In addition, basic and applied research efforts are directed toward further characterizing the pathophysiology, host response, epidemiology, and behavioral aspects of these diseases to permit the development of improved diagnostic, prevention and control methods.

The major Federal foci for assistance to States are the Centers for Disease Control (CDC) and the HHS Regional Offices; and for research, are the CDC and the National Institutes of Health, including the National Institute of Allergy and Infectious Diseases (NIAID), the National Cancer Institute (NCI), and the National Institute for Child Health and Human Development (NICHD).

II. BACKGROUND

Preventing the spread of human immunodeficiency virus (HIV) and controlling the development of AIDS remains the Nation's number one public health priority. Since its transmission is primarily sexual, HIV has become the predominant STD. Currently, an estimated 1 million Americans are infected with HIV. In addition to HIV infection, STD, which threaten the health of primarily adolescent and young adult Americans each year, have increased to 12 million cases. Nationally, it is estimated that there are nearly 4 million chlamydial infections, 1.4 million cases of gonorrhea, about 130,000 new cases of syphilis, 1.2 million cases of nonchlamydial-nongonococcal urethritis, 1 million cases of

nonchlamydial-nongonococcal mucopurulent cervicitis, 200,000 to 500,000 cases of genital herpes, 270,000 to 300,000 cases of hepatitis B, 3 million cases of trichomoniasis, and 500,000 to 1 million cases of human papillomavirus infections. Over 750,000 cases of PID are diagnosed and treated each year resulting in approximately 180,000 hospitalizations (43 percent of these are younger than age 25 and 84 percent are younger than age 35), over 77,000 major surgical procedures (including almost 26,000 hysterectomies), and over 88,000 ectopic pregnancies each year.

Women and children bear an inordinate share of the physical and emotional burden of STD. Involuntary infertility, much of which is secondary to STD, has continued to increase with 350,400 visits to physicians for infertility services in 1990. Prenatal STD also produces adverse effects on both pregnancy outcome and maternal/infant health, many of which are entirely preventable. Approximately 111,000 babies born each year will have chlamydial infection. For pregnant women with untreated syphilis, the risk of death of the infant is 40 percent, of delivery of an infant with congenital syphilis is 40 percent and of the delivery of a normal infant only 20 percent. As many as 3 of every 10,000 newborns are infected with herpes; more than 40 percent of those not treated will die and half of the survivors will suffer serious and permanent mental damage. Congenital infection by cytomegalovirus (CMV) is estimated to occur in 1.5 percent of all pregnancies, and group B Streptococcus is estimated to cause symptomatic disease in 12,000 infants under 3 months of age annually and to cause nearly 5,000 infant deaths.

III. EFFECTIVENESS

Since the initiation of Federal assistance and efforts to control STD, reported cases of syphilis have declined 76 percent from an all-time high of 575,600 in 1943 to 137,400 in CY 1990. During this same period, first admissions to mental hospitals for syphilitic psychoses have declined by 8 percent and infant deaths caused by syphilis have declined 99 percent. In FY 1990, the estimated savings from syphilis prevention activities was \$13.6 million. However, reported infectious syphilis in FY 1990 was exceeded only by gonorrhea and chicken pox. The reported incidence of primary and secondary syphilis increased by 14.6 percent in CY 1990 and represents the highest number of reported cases in any year since 1948! All the increase has occurred in low-income, inner-city, heterosexual minority populations. Syphilis rates are 52 times higher among black males and 10 times higher among hispanic males than white males. Rates among black women have increased 192 percent since 1984, from 33.3 to 97.2/100,000! Morbidity is also concentrated with 61 percent of reported cases occurring in only 35 counties. Syphilis in white homosexual males has decreased since 1982 and remains at low levels. This decrease is due in large part to favorable changes in sexual behavior among homosexual men in response to the AIDS epidemic. The increases experienced for the past three years have been associated with a complex set of factors including: increased transmission among hard-to-reach groups such as "crack" cocaine users who are exchanging sex for drugs and money; a decline in socioeconomic and educational levels in certain high-risk populations; decreased access to and utilization of health care; and changes in priorities and overburdening of public health department STD programs.

The current epidemic of primary and secondary syphilis in heterosexual populations has resulted in substantial increases in congenital syphilis. Congenital syphilis is an important sentinel health event that is preventable if women receive appropriate prenatal care. Reported congenital cases increased to 7,219 in FY 1990, reflecting a 313 percent increase over the 1,747 cases reported in FY 1989.

Before 1989, only the most clinically apparent cases of congenital syphilis were detected by the surveillance system. Many infants, who were asymptomatic but presumptively treated at birth, were not included. Stillbirths, the most extreme outcome of untreated syphilis in pregnancy, were also excluded. In 1989, a new surveillance case definition for congenital syphilis was introduced. The new definition includes all pregnant women with untreated syphilis who come to delivery. Both liveborn and stillborn infants are included. The new definition should allow better assessment of the population at greatest risk.

The large increases in congenital syphilis cases in 1989 and 1990 are due in part to the increasing use of the new case definition. In 1989, approximately 1,000 (57 percent) of the 1,747 reported cases would not have been included using the old case definition. New York City, one of the few areas using the new case definition in 1989, reported 1,017 of these. In 1990, approximately 6,400 (87 percent) cases would not have been included by the old case definition.

Gonorrhea continues to be the most reported communicable disease in the United States. Federally-assisted State and local gonorrhea control programs were implemented in FY 1972. Within one year, over 8 million women who were receiving pelvic examinations for other reasons were also screened for gonorrhea; this number has fluctuated between 5.1 and 8 million each year since then. From FY 1976 through FY 1981 the number of reported cases stabilized. Since 1981, cases of gonorrhea have decreased by over 30 percent despite social changes which placed increasing numbers of people at risk for STD. Reported gonorrhea decreased by 4.5 percent in 1990, the 5th consecutive year of decline. Male cases decreased by 7.9 percent, but female cases increased by 0.2 percent. The benefit to cost ratio of screening and outreach activities for gonorrhea is estimated to be 2.9:1.

In FY 1989, antimicrobial resistance remained a widespread and complex problem. Almost 65,000 cases of antibiotic resistant gonorrhea were reported, an increase of 22 percent over 1989. Over 9 percent of gonorrhea cases reported in 1990 were resistant. Because of this large proportion of resistance, the STD Treatment Guidelines were revised so that ceftriaxone is now recommended for all cases of uncomplicated gonococcal infection.

IV. PREVENTION AND CONTROL EFFORTS

The CDC provides active leadership and support for national efforts directed toward the control of STD to include: a national system to identify, investigate and monitor special disease control problems; the timely transfer of technological advances to improve State and local prevention and control programs; and applied research to develop new information about diagnosis, treatment, prevention and control of all STD.

Project grants awarded to State and local health departments and appropriate public and nonprofit entities emphasize the reduction of morbidity and mortality from STD through the development of prevention and control strategies and the implementation of nationally coordinated control programs focused on disease intervention activities. The basic control program components are: (1) health promotion efforts directed toward people at risk to change high-risk behaviors, prevent exposure and influence the infected to seek prompt medical care for themselves and their sex partners; (2) surveillance systems to monitor STD among specific populations; (3) surveillance and control activities directed toward antibiotic resistance; (4) hospital-based surveillance efforts for PID; (5) screening high-risk populations; (6) sex partner notification services, (7) developing strategies for controlling STD and providing training for clinical skills improvement; and (8) involving the private medical community in all aspects of STD control.

Syphilis control efforts focus on disease-intervention activities including surveillance, case detection, and prevention, specifically of congenital syphilis. Follow-up of reactive serologic tests for syphilis resulted in the reporting of over 50,700 previously unknown/untreated cases of syphilis. During 1990, sex partner notification efforts provided to individuals with infectious syphilis resulted in 19,600 new cases of syphilis being identified and treated and 43,200 exposed sex partners receiving preventive treatment. These screening and outreach efforts prevented an estimated 12,000 new cases of syphilis. Clearly, however, these activities continue to fall short of the ideal of control, i.e., reduction of morbidity in the populations at highest risk. One potential solution to this dilemma has been to concentrate human and financial resources in the 35 counties which account for the majority of infectious syphilis cases and to focus on coalition building activities in those communities at highest risk.

National policy guidelines for the prevention and control of chlamydial infections were promulgated in 1985 and will be revised in 1991. Since then, STD control programs have made substantial advances in the development of prevention and control programs for chlamydia. Forty-four have at least one city or county STD Control Program that offers comprehensive surveillance, diagnostic testing and treatment services, and 40 States also have laws or regulations requiring the reporting of chlamydia. Chlamydia control efforts implement a series of interventions similar to those used in gonorrhea control and include: use of erythromycin for eye prophylaxis in newborns to prevent both gonococcal and chlamydial ophthalmia neonatorum; incorporation of information on the recognition and management of clinical syndromes caused by C. trachomatis into medical training programs; treatment of chlamydia infections which frequently coexist with gonococcal infections by employing a gonorrhea treatment regimen effective against both organisms; and using antichlamydial regimens for the treatment of sexual partners of patients who have clinical syndromes consistent with chlamydial infection.

Prevention and control efforts saved an estimated \$12.5 million in uncomplicated chlamydia and \$50 million in chlamydial PID in 1990. While these figures are substantial, they are insignificant in terms of what

savings could be effected if a comprehensive chlamydia prevention and control program were implemented.

V. HEALTH PROMOTION

All sexually transmitted disease control project grants to State and local health departments include information and education activities as an integral portion of their control strategies. Control programs emphasize clinic based patient education/counseling designed to avoid future risk of infection and to improve health seeking behaviors on the part of infected patients. Community education efforts are directed toward high risk groups, such as pregnant females, homosexual men, adolescents, and intravenous drug users. Education efforts are also directed toward school based populations, particularly in the implementation of effective STD/HIV curricula within the Nation's school systems. The effectiveness of health promotion activities varies. For example, homosexual males have apparently changed their high risk behavior as morbidity for infectious syphilis and gonorrhea have decreased steadily among this population over the past three years. Unfortunately, the same messages delivered to the heterosexual core populations have not been as effective since infectious syphilis rates in this population have increased significantly in the past three years. Alternate health promotion approaches including the direct funding of community based organizations who represent and serve these populations are being developed for this segment of the population.

GDC's ongoing contract with the American Social Health Association to operate the National STD Hotline resulted in STD information and referral services to over 120,000 callers in 1990!

VI. CLINICAL SERVICES/TRAINING

Adequate clinical management of patients and their partners is the final common pathway of STD control. Unfortunately, clinical services vary widely in different settings and are often inadequate to provide appropriate care for STD patients. The objectives of ideal clinical management are: 1) to determine the most likely etiology of the patient's complaint; 2) to provide appropriate treatment for that condition; 3) to detect other STD; 4) to ensure patient follow-up for test of cure after treatment; 5) to manage properly those patients who failed treatment; 6) to identify sexual partners for appropriate evaluation and treatment; and 7) to educate patients to reduce their risks of further disease acquisition. Thus, all key STD control strategies are contained in the microcosm of clinical services.

Since medical school curricula in the United States have not kept pace with the increasing incidence of STD, an integral part of STD control strategies has been to develop a coordinated system for training health care providers in this rapidly changing field. To this end, STD Prevention/Treatment Centers have been established at 11 sites. Each center is based on integration of a university medical school with a model public STD clinic for purposes of providing training for health care providers, and medical and nursing students. By FY 1990, almost 25,000 students had been cumulatively trained since 1979.

VII. RESEARCH

Both basic and applied research are crucial to STD control. Major changes in intervention strategy have accompanied the introduction of new antibiotics (e.g., penicillin), the development of better detection methods (e.g., Thayer-Martin media), the identification of resistant organisms (e.g., PPNG, CMRNG, TRNG), and the recognition of high-risk groups (e.g., homosexuals, patients with repeat infections, women with PID). Presently, quantum leaps in STD control programs await such developments as effective vaccines against HIV infection, herpes, or gonorrhea or more effective interventions with drug using subcultures. Most STD research in the United States is supported by NIH and CDC, although an increasing amount is funded either by voluntary organizations concerned with the magnitude of the STD problem or by pharmaceutical firms or medical diagnostic companies aware of the potential market. The objectives of this research are to characterize the pathophysiology, host response, and epidemiology of STDs to allow further development of improved diagnosis, treatment, prevention and control strategies.

NIH supports a variety of basic science and clinical projects. These include development of gonococcal and herpes vaccines, experimental clinical trials with antiviral agents, determination of STD pathogens which predispose for HIV infection, establishment of herpes transmission patterns within communities, and determination of host responses to chlamydia infections. During 1990, NIH issued an invitation to investigators to compete for a new research approach which incorporates a broadened view stressing expansion beyond the microbiologic frontier to the behavioral, epidemiologic and operational research areas. These Cooperative Research Centers represent a long term investment in stimulating a multidisciplinary research team which involves everything from continued biotechnical "bench science" research to innovative community outreach programs and demonstration projects. NIH also sponsors training of post-doctoral fellows in clinical and microbiologic STD research and has undertaken periodic workshops to update the most rapidly advancing areas of STD knowledge. The CDC, through the Division of STD/HIV Prevention (DSTD/HIVP) and the Division of Sexually Transmitted Disease Laboratory Research (DSTDLR), conducts applied research directed toward monitoring practical results and evaluating control strategies. This involves behavioral studies, clinical research, epidemiologic studies, and programmatic investigations.

VIII. PROGRAM ACCOMPLISHMENTS, FY 1990

A. Syphilis

- o Initiated multisite, prospective, follow-up study to investigate the effect of co-infection on initial manifestations and response to treatment of syphilis.
- o Implemented the use of a new case definition for congenital syphilis on a nationwide basis.
- o Continued system for reporting unusual manifestations of syphilis in HIV infected patients.

- o Conducted six outbreak investigations of syphilis.
- o Continued study of natural history of syphilis in HIV-infected patients.
- o Continued a retrospective study of the natural history of syphilis among 710,000 patients treated at Staten Island.
- o Identified and treated 50,700 previously unknown/untreated persons with reactive tests for syphilis.
- o Conducted sex partner notification activities that resulted in 19,600 new cases detected and almost 43,200 patients preventively treated.
- o Conducted outreach efforts in syphilis control that resulted in the prevention of 12,000 new infections.

B. Gonorrhea

- o Maintained 21 isolate monitoring laboratories to conduct surveillance of antibiotic resistance.
- o Cultured 5.1 million women; of these, 188,200 (3.7 percent) were positive and 81 percent were located and treated.
- o Examined 122,000 sex partners.
- o Conducted outreach efforts in gonorrhea control that resulted in the prevention of 97,300 new infections.
- o Continued diagnosis/treatment, epidemiology, and prevention/control research studies.

C. Chlamydial Infection

- o Continued nationwide implementation of national policy guidelines for prevention and control of chlamydia.
- o Finalized a plan to initiate sentinel surveillance of chlamydial infections using an approach analogous to HIV Family Of Surveys.
- o Continued risk factor study in family planning and prenatal clinics in Washington, Alaska, Oregon and Idaho.
- o Tested 1.5 million women and 486,000 men for chlamydial infection; of these 136,000 women (9 percent) and 51,700 men (11 percent) were positive.
- o Conducted outreach efforts in chlamydia control that resulted in the prevention of almost 54,000 new infections.
- o Studied the respective contributions of antimicrobial resistance, latency, and reinfection to the high rate of recurring infection following treatment.

- o Continued a study at Emory University to evaluate the role of chlamydia infection on ectopic pregnancy.

D. Human Papillomavirus (HPV) Infection

- o Analyzed cervical cancer mortality trends which show that mortality rates have begun to increase among young women.
- o Continued ongoing collection system with a large commercial cytopathology laboratory to develop a surveillance system for cervical HPV infection.
- o Continued research on the epidemiology of external genital wart infections.
- o Continued study of the natural history of cervical HPV infection in Native American women.
- o Conducted a survey of knowledge, attitudes and beliefs about genital warts among women attending STD and adolescent clinics in Denver which showed that 78 percent of patients were well informed.
- o Completed a study in Albuquerque to assess the role of specific HPV types and other risk factors for progression to more severe cervical abnormalities.

E. Herpes Simplex Virus Infection (HSV)

- o Continued study to determine the association of the presence of antibody to HSV-I and protection against infection with HSV-2.
- o Continued cooperative studies to further define the epidemiology and natural history of HSV.
- o Continued collaborative effort with FDA and pharmaceutical industry to monitor teratogenicity to acyclovir.
- o Collected serum samples from the NHANES III survey to be tested for HSV-2 antibody and compared to prevalence results of NHANES II, which showed that 16 percent of the U.S. population were infected with HSV-2.
- o Completed study in Atlanta which found that HIV was associated with serologic evidence of syphilis, but not HSV-2 infection.

F. Other STD

- o Implemented study in New York to investigate the increase in Kaposi's sarcoma among men who are not infected with HIV.
- o Continued to fill CDC's unique role of providing clinical, laboratory, and epidemiologic competence for chancroid, a disease of low but increasing incidence.

- o Continued a case control study to determine risk factors for the acquisition of chancroid.
- o Continued surveillance of metronidazole resistance for T. vaginalis. In 1990, 15 States submitted resistant strains for testing; 93 percent of isolates tested were resistant.
- o Implemented a pilot program of free hepatitis B vaccine distribution in San Francisco STD clinics to determine if patients would accept the initial vaccination and return for boosters.

IX. PLANS FOR FY 1991

STD priorities are continually evolving as new STD emerge as serious public health problems and require innovative approaches to diagnostic, prevention, therapeutic, and case management services. A major activity of the Division will be to coordinate a meeting of professionals in the field of clinical diagnosis, behavioral, and epidemiologic aspects of STD to review current trends and to make recommendations about future prevention and control strategies.

The prevention and control of infectious and congenital syphilis, gonorrhea, and chlamydia will continue to be a major foci for control efforts in FY 1991. Because of the association between genital ulcer disease and sexual HIV spread and the increase of both syphilis and chancroid occurring in populations already with a high prevalence of HIV secondary to illicit drug use, it is crucial to again ensure in FY 1991 that HIV prevention activities both dovetail with and support genital ulcer disease control activities.

Education, the primary prevention tool available, will continue to focus on high-risk populations, particularly inner-city heterosexual minorities, STD patients, IV drug abusers, providers of medical care services, and the general public. Prevention/education efforts will also seek to network with community based organizations representing groups at risk, especially minority groups, to use resources in the most efficient manner possible.

Interviewing/counseling of selected persons with STD will be provided, especially to young patients with their first STD infection, to patients with repeat infections, to patients with resistant gonococcal infections or other complications and to those at high risk of acquiring HIV infection.

Technical assistance and consultation to State and local health departments will continue to emphasize improving diagnostic, clinical, and management techniques. HIV health education/risk reduction techniques will continue to be a focus of STD control programs.

The surveillance system to measure antibiotic resistance levels established at 21 laboratories will be continued.

Efforts to standardize, expand and upgrade the quality of data collection, analysis, interpretation and use at the Federal, State and local level will be continued. The microcomputer-based data network (MIS) will be further

refined in all State and selected local health departments, with a statewide pilot microcomputer network being expanded in California and implemented in Florida.

Training efforts in FY 1991 will focus on the further development of clinical experience in STD for students during their medical school and residency years. Existing STD Prevention/Training programs will be adjusted as new information or needs are identified and to ensure maintenance of the highest public health and clinical care standards.

STD management will emphasize additional skills in epidemiology to set priorities and provide the maximum yield per STD dollar invested.

National population-based research on the distribution of sexual behavior patterns across population sub groups will continued to be emphasized because of the priority of the incurable viral STD.

Research to highlight the prevention of STD syndromes of greatest public health concern -- infertility, ectopic pregnancy, pelvic inflammatory disease, and adverse reproductive outcomes -- will be continued. Clinical trials of promising therapeutic alternatives for infections caused by resistant organisms will be continued. Studies to better define the problem of Chlamydia trachomatis and to seek public health applications of existing and new technologies will be continued. Behavioral research to evaluate existing activities and to develop new interventions to assist those at highest risk adopt safer sex behaviors will be continued. Finally, the CDC will also continue research to identify and reduce the incidence of unplanned infertility attributed to STDs.

PUBLIC HEALTH SERVICE AND GOVERNMENT-WIDE

SUBSTANCE ABUSE

Budget Authority/Obligations

	1988 Actual	1989 Actual	1990 Actual	1991 Appropriation	1992 Pres Budget
Health and Human Services					
ADAMHA.....	\$731,027,000	\$1,124,583,000	\$1,774,748,000	\$2,024,804,000	\$2,146,009,000
HRSA.....	465,770	304,906	196,807	414,990	---
IHS.....	45,535,000	49,859,000	65,839,000	73,952,000	86,256,000
CDC.....	13,100,000	20,000,000	25,229,000	29,334,000	29,334,000
HCFA.....	445,000,000	490,000,000	610,000,000	680,000,000	750,000,000
FDA.....	1,600,000	7,000,000	7,200,000	7,400,000	7,600,000
FSA.....*	---	3,000,000	1,990,000	---	---
HOS.....*	---	30,000,000	39,468,000	64,574,000	64,574,000
Subtotal, HHS.....	1,236,727,770	1,724,746,906	2,524,670,807	2,880,478,990	3,083,773,000
Office of National Drug Control Policy.....*	---	3,500,000	12,100,000	17,600,000	20,200,000
High Intensity Drug Trafficking Areas.....*	---	---	25,100,000	82,000,000	50,000,000
Special Forfeiture Fund....*	---	---	---	46,000,000	77,000,000
Labor.....	3,100,000	38,600,000	46,000,000	74,500,000	83,000,000
Education.....*	229,800,000	376,300,000	602,800,000	679,100,000	713,400,000
Agriculture.....*	6,500,000	6,500,000	6,700,000	16,200,000	15,800,000
Defense.....*	200,600,000	501,600,000	799,100,000	1,105,300,000	1,158,600,000
Veterans Affairs.....*	88,500,000	242,000,000	305,600,000	368,200,000	407,000,000
Justice.....*	1,436,500,000	2,470,600,000	3,828,000,000	3,820,900,000	4,425,300,000
Treasury.....*	484,500,000	702,500,000	906,800,000	900,600,000	950,600,000
Transportation.....*	520,200,000	643,000,000	688,900,000	755,000,000	748,000,000
State.....*	114,100,000	141,800,000	307,300,000	462,400,000	611,700,000
Interior.....*	9,600,000	13,400,000	29,400,000	38,200,000	47,100,000
ACTION.....*	5,900,000	10,100,000	10,500,000	10,900,000	11,100,000
White House Conference.....*	2,500,000	---	---	---	---
Housing and Urban.....*	---	8,200,000	106,500,000	150,000,000	165,000,000
US Courts.....*	N/A	208,800,000	258,100,000	337,000,000	424,400,000
Total, Substance Abuse.....	\$4,338,527,770	\$7,091,646,906	\$10,457,570,807	\$11,744,378,990	\$12,991,973,000

* Reported data excludes alcohol abuse funding.

ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH

Substance Abuse

National Institute on Drug Abuse

Neuroscience and Basic Biological Research

A thorough understanding of the relationship between brain mechanisms that underlie behavior and how these processes are changed by drugs is essential to understanding drug abuse. It is also important for developing rational treatments for drug abuse and any resultant disease. Studies in basic research investigate cellular mechanisms and humoral (whole body) responses to drugs of abuse. Advanced biomedical technology is often used to explore previously inaccessible regions of the brain. Advances in tissue culture techniques have permitted close control, observation, and quantitation of effects of drugs of abuse on well-identified cell types.

Neuroscience: A major breakthrough in culturing brain cells was reported this summer. Researchers at Johns Hopkins University established a human cortical neuronal cell line. The original tissue was obtained from a patient with a disorder associated with continued proliferation of immature neuronal cells. When differentiated in culture, these cells display mature neuronal morphology and biochemical markers; this is expected to facilitate characterization of central nervous system neuronal function. Neurotransmitter uptake; biosynthetic enzymes involved in the processing of these peptides; receptors, especially as they appear during differentiation and the effects of drugs of abuse on this process; and second messenger systems, especially CAMP and phosphoinositol turnover systems will be studied. These studies could provide the groundwork for significant progress in elucidating the basic neurochemical mechanisms of drug actions.

Neurochemical mechanisms can be "watched" with the aid of sophisticated new technology. Investigators at the Intramural Addiction Research Center reported the use of positron emission tomography (PET) scanning to determine which brain areas are affected by morphine and which by cocaine. Morphine or cocaine, at doses that produced euphoria, reduced glucose utilization (an index of cellular activity) in the cerebral cortex. Findings from this study help to pinpoint the sites of action of cocaine and morphine and suggest that a reduction in cortical activity may be part of the mechanism by which abused drugs produce euphoria. Understanding the mechanisms that produce euphoria and locating sites of drug action may lead to interventions designed to halt the initiation and maintenance of drug use.

Basic Biological Research: Evidence is accumulating that cocaine can cause massive heart failure, even in otherwise healthy individuals, and at low doses. In a recent research paper, NIDA-

supported researchers reported that immediately following intravenous injection of cocaine in conscious dogs, severe transient slowing of the left ventricle of the heart occurred. The observed decreases in blood flow were accompanied by increases in heart rate, mean blood pressure, and coronary blood flow. They also observed a cocaine-induced heart slowing in sedated dogs that was similar to that observed in conscious dogs. However, the slowing of left ventricular contractions in sedated dogs was not associated with changes in heart rate, blood pressure or coronary blood flow. These findings clearly suggest that cocaine-induced heart failure is the result of its local anesthetic action on the heart muscle; and that this slowing occurs even in the presence of intense adrenergic stimulation.

Treatment Effectiveness

Drug abuse treatment has proven to be effective under several circumstances. Exactly which constellation of services in differing treatment modalities are effective, why, and for whom is under intense investigation. Several approaches to optimizing treatment are being employed. Psychosocial, biologic (medication), and health services approaches are being carefully explored and fully developed.

Psychosocial: Matching client needs to therapeutic modality is important for enhancing treatment retention and outcome. Based on the kind of chemical addiction and client gender, preliminary reports have found differences in the prevalence of personality disorders. A recent study of 140 patients who had come for short-term, intensive treatment for (DSM-III-R) cocaine and/or alcohol use disorders at a specialized addiction unit. Significantly more cocaine compared with alcohol dependent patients met the criteria for a personality disorder, regardless of gender. Specifically, while self-defeating personality disorder was most prevalent for alcohol dependent females, paranoid, borderline, and histrionic disorders were most prevalent for cocaine dependent females. Interestingly, avoidant personality disorder was prominent in all subject groups. The stability of these diagnoses with time, particularly after intensive rehabilitation, is currently under investigation. If these diagnoses remain stable, using DSM-III-R, Axis II criteria for evaluation of incoming patients may expedite the matching of client needs to therapeutic modality.

One dilemma confronting treatment practitioners is whether there is a difference between inpatient and outpatient treatment efficacy. A NIDA-supported project has conducted a preliminary investigation of the efficacy of outpatient behavioral treatment for cocaine dependence. Treatment duration was three months and involved two integrated components: 1) participation in a four day per week urinalysis monitoring and contingency-management program emphasizing positive reinforcement for cocaine abstinence; and 2) simultaneous participation two times per week in individual and couples therapy adapted from the Community

Reinforcement Approach, which has been shown to be effective with alcoholics. Patient response to this treatment has been very encouraging: no dropout and an overall average of 85 percent cocaine-free urines. This treatment regimen appears to hold much promise as an effective treatment for one of society's most serious public health problems.

Another study indicated little evidence that inpatient treatment was more effective than day hospital. This investigation is using a randomized assignment of day hospital versus inpatient treatment for cocaine abusing men at a Veterans Hospital. Baseline Addiction Severity Index (ASI) characteristics and four and seven month post-treatment entry outcome findings showed little difference between treatment modalities. The treatment completion rate, however, was significantly higher for inpatients than for outpatients. Few group differences were revealed in follow-up evaluation scores at four and seven months post-treatment entry; however, considerable improvement was shown by both groups in substance abuse problem levels. Both patient groups showed significant improvements in legal, family/social and psychological problems. Thus, there is a clear indication that both treatments were reasonably effective.

A major effort seeking to correlate treatment outcomes with treatment modality is the Drug Abuse Treatment Outcome Study (DATOS). This study is collecting data on 20,000 individuals entering five treatment modalities in 50 treatment programs over a 5-year period. Information is being collected from interviews conducted at treatment entry, during treatment, and upon leaving treatment. Patient interviews will be supplemented with clinical assessments of psychological, social, and physical impairments in addition to drug and alcohol dependence. Treatment outcomes will be compared for clients entering treatment with varied patterns of drug abuse and levels of psychosocial impairment. One area of special interest is in determining how well client needs are matched to therapeutic modality. A DATOS specifically analyzing treatment modalities designed for adolescents is in the late planning stage.

Medications Development: In FY 1991 the NIDA established a Medications Development Division to coordinate and direct the development of new pharmacological agents for the treatment of substance abuse and addictive disorders, including injection drug abuse. The development of new medications is an extraordinarily complicated activity that is approached through a complex, collaborative effort involving government scientists at NIDA and the Food and Drug Administration, academic laboratories, and the pharmaceutical industry.

The development of new pharmacotherapies is, by its very nature, a long process requiring from seven to eleven years for completion. In an effort to develop new therapies as quickly as possible, NIDA is evaluating potential treatment agents that have been developed for other brain or behavior disorders to determine

whether they might prove of value in treating heroin and/or cocaine addiction. Other potential medications are being identified through a grant and contract program in synthetic chemistry, through contacts with the pharmaceutical industry, and through the creation of a large chemical database. Collaborative efforts have been initiated with NIH Institutes that have expertise in the development of novel medications.

Health Services Research: Research into treatment effectiveness has been expanded with projects investigating availability of services, associated costs, and the development of a client-based database. Passage of the Anti-Drug Abuse Act of 1988 created new opportunities to expand these activities. All facilities that receive Federal or State funds will be required to furnish client-level data. This should substantially enhance acquisition of data for drug abuse services research. Additionally, the National Drug Abuse Treatment Unit Survey (NDATUS) is now conducted annually. In order to address policy concerns posed by ONDCP, new questions such as the number of clients receiving methadone, and the number of pregnant clients have been added.

One major survey conducted during FY 1990 is the client-based Drug Services Research Survey (DSRS). DSRS is designed to supplement information from the 1989 NDATUS by obtaining information on drug abuse treatment providers and characteristics of their client population. The survey consists of two major components, a facility-based survey of 1,000 providers and a person-based survey of 2,400 clients discharged from treatment. The second component of DSRS is a subsample of 120 programs that will be selected for site visit to verify information collected in the telephone survey. Enhanced facility information on admission policies, waiting lists, reimbursement policies, and costs will also be collected at this time. This on-site data collection is designed to provide representative client-level data. Client-level items to be abstracted include demographic characteristics, prior treatment history, drug use history, treatment characteristics including length of time in treatment, and discharge status.

At the request of NIDA, the Institute of Medicine (IOM) has completed a report on the extent and adequacy of drug treatment services. This report, titled Treating Drug Problems, assessed: 1) the extent to which the cost of substance abuse treatment is covered by private insurance, public financing, and other sources; and 2) the adequacy of such coverage for the treatment of substance abusers. The IOM also made recommendations regarding financing and reimbursement for drug treatment, and future research related to public and private insurance. The recommendations include more effective treatment for those in need of treatment, expansion of high quality public care, more effective public and private financing, and expansion of health services research.

Prevention

Five major types of prevention programs have been evaluated: Knowledge Only, Affective Education (self-esteem building, values clarification, etc.), Peer Education (combination of knowledge and peer leadership, peer teaching, and positive peer pressure groups), Knowledge plus Affective Education, and Alternatives (wilderness training, personal competence development, etc.). A recent review of these programs concludes that most drug prevention programs can significantly increase knowledge concerning the negative effects of drugs; drug prevention programs that utilize positive peer groups can produce, in the general adolescent population, clinically-significant increases in drug knowledge, anti-drug attitudes, and reductions in drug use; and Alternatives programs produce comparably positive effects to peer group programs, particularly for high-risk youth.

More recently, comprehensive prevention programs have combined multiple approaches. A good example is the Midwestern Drug Abuse Prevention Research Project, which is assessing the efficacy of a comprehensive drug prevention program for middle school students. Interventions were implemented sequentially at each site, with one new intervention added each year. The first intervention has a mass media focus and is used to both heighten community awareness and to introduce the new intervention being implemented by the program. During the first year, the project introduced a school-based peer resistance program called STAR (Students Taught Awareness and Resistance), which consists of ten classroom and homework sessions focused upon the health consequences of drug use; correction of normative myths concerning the prevalence of drug; social resistance training; assertiveness and problem solving training; and a statement of public commitment to avoid using drugs. The remaining three interventions include parent/family drug education and organization, development of community drug prevention task forces, and activities to change drug prevention-related health policies in the community.

Four-year follow-up results from this project have just been reported. These data suggest that program effects resulted in a 25 percent reduction in marijuana use. In addition, preliminary analyses of cocaine use suggest that non-program participants were more than twice as likely to have used cocaine as were program participants. This research indicates that the decrease in cocaine use may be partially explained by reductions in cigarette and marijuana use by students exposed to the program.

Epidemiology

In order to measure the nature and extent of drug abuse in the U.S. and among its various populations, NIDA conducts and supports research and surveys on the incidence, prevalence, morbidity, mortality, and other adverse health consequences of illicit drug use.

Surveys: A major new project was started to study drug abuse in metropolitan areas in-depth, starting with Washington, D.C. An important focus of this Metropolitan Area Study is the development of methodologies to collect data on hard-to-measure populations missed by many traditional survey techniques. The periodicity for both the NDATUS and the National Household Survey has been increased from biennially to annually, and the National Household Survey was modified to include metropolitan area subsamples (starting with Washington, D.C. in 1990) and to perform methodological studies designed to improve the quality of data collected.

Since 1986, the Drug Abuse Warning Network (DAWN) has been in the process of being transformed into a nationally representative sample of hospital emergency rooms. In 1990, preliminary weighted estimates from DAWN became available, providing national and metropolitan area estimates of drug-related episodes for 1989.

Data on individual clients have not been routinely collected, making it very difficult to characterize this population. The Minimum Client Data Set project was initiated with grants to the states to support revisions in their data systems and with a contract designed to develop the system for the national data base. NIDA has collaborated with NIAAA and the various State agencies to design a vehicle to gather and record data collected at the state level. A significant result of this collaboration is agreement among the participants on a set of national standards for data collection on treatment related data. This agreement will permit nationwide comparability of data sets. Full implementation, with all states participating, and with at least one year's data, is scheduled for the end of 1991.

Outbreak Investigations: Outbreak investigations and field studies are an integral part of NIDA's surveillance program. Initiation of outbreak investigations and field studies is in response to information from field and epidemiology network sources such as NIDA-sponsored Community and State Epidemiology Work Groups; NIDA, state and local networks; or in response to trends observed in drug use indicators.

Methamphetamine smoking was identified as an emerging problem in Hawaii during the last half of 1988. At the request of the Hawaii Department of Health a field studies team from NIDA conducted an outbreak investigation during February and March of 1989 to characterize the epidemic and to and document the extent and trend of the problem. A follow-up data collection was initiated during February of 1990, at which time information was abstracted from treatment records and State treatment admission and discharge summary forms. In addition, a group of methamphetamine smokers currently in treatment were interviewed about their symptomatology and patterns and preferences of drug use.

Findings from the review showed the use of d-methamphetamine hydrochloride in a large crystalline form by the smoking route ("ice") to be almost exclusively limited to Hawaii. Widespread transfer of this trend of use in other areas of the U.S. has not been documented, although methamphetamine use by other routes continues to be popular along the West Coast. Short and long-term health and social consequences including permanent neural toxicity of methamphetamine use was explored. It is hoped that future research endeavors will be stimulated by this information exchange.

Drugs and Crime

During the past year NIDA has actively funded research projects seeking to explore the drug-crime connection. Findings from this research have been utilized by policymakers, drug enforcement officials, and health and human services providers to develop effective strategies in their struggles with illicit drug use and drug-related criminal activities.

An interesting study on how drug offenders choose their victims has yielded preliminary results. The vast majority of the 50 individuals already interviewed felt that the probability of arrest did not influence their decision to commit crimes. Crack addicts in particular appeared to pay virtually no attention to environmental/situational crime prevention efforts; in addition, they appeared to possess an air of invincibility according to observations from the principal investigator on this project. Overall, most of the subjects interviewed believe that owners of property can do little or nothing to prevent crime, and many of the subjects have devised elaborate and inventive schemes to circumvent extensive protective measures.

Additional findings from the Inciardi delinquent drug abuser project, which has been investigating the criminal activities of a group of 600 seriously delinquent crack users, has reported that these youth were involved in approximately 429,136 criminal offenses per year. Of these offenses, 18,477 were considered to be major felonies. These results indicate that, on average, each of the interviewed youth were perpetrators of over 30 serious offenses per year. Overall, youth who were heavy crack users were more likely to be involved in a greater number of criminal activities than those who were infrequent crack users.

Technology Transfer

In 1990, NIDA launched a major technology transfer initiative to ensure that new technologies resulting from research are adapted by the drug abuse prevention and treatment community. Through various methods, such as monographs, videos, and conferences, NIDA communicates its research findings (including effective skills, techniques, models, and approaches) to the field, thus, translating this knowledge into practical applications for treatment programs.

In addition, planning is underway for a major national technology transfer conference to be held in January 1991. This conference will examine new methodologies for treatment programs. Topics will include HIV disease and drug abuse programs, special services in response to the special needs of women in treatment, improving the quality of methadone maintenance, and vocational rehabilitation.

Another important project, overcoming barriers to treatment, was established in November 1988, and is designed to encourage acceptance of drug treatment facilities within communities. This project provides technical assistance to communities for promoting awareness of the benefits of drug abuse treatment. The project is also working with drug abuse treatment providers who are trying to open new treatment facilities. The Institute hopes to convince people that treatment is a critical part of the solution to the Nation's drug problem, and that drug abuse treatment facilities are as essential to the health and well-being of the community as fire stations, schools, and hospitals.

Local citizens are understandably concerned about reduced property values, safety, and crime if new drug abuse treatment facilities are located in their neighborhood. Research has demonstrated that these attitudes can be changed with more education about what treatment is; what it does; and why it is important. To address these needs, this year NIDA developed four television and eight radio public service announcements, which are being distributed nationwide. A series of print ads also was developed. All materials convey the slogan "Drugbusters Don't Let Drugs Win". This project is currently active in nine cities and is planned to reach 24 cities by November 1991. An integral portion of this project is an evaluation component, the preliminary results of which are expected by the end of 1991.

Workplace Policy Research

NIDA administers an interdisciplinary research program on drugs in the workplace, and other activities are conducted related to drug-free workplace policy, program development, implementation, and assessment. Research includes studies assessing the effects of drug-free policies on workplace drug use and studies assessing the prevalence, etiology, and impact of drug abuse in the workplace. NIDA provides technical assistance and guidance to Executive Branch agencies in their efforts to implement Executive Order 12564, which requires a comprehensive written plan to deal with drugs in the workplace. NIDA also provides uniquely tailored counseling to business, industry, and unions on how to establish and implement a drug-free workplace program through the operation of the Drug-Free Workplace Helpline; sponsors a series of workshops for small business owners on a drug-free workplace; and publishes numerous publications that support public and private sector employers' efforts to eliminate the adverse effects of drugs in the workplace.

Office for Substance Abuse Prevention

Drug use has become a major problem in the United States, affecting many facets of American life. Although recent national surveys have found dramatic reductions in the overall numbers of Americans using drugs, these gains are offset by evidence of increasingly pathological addictive drug use among segments of our society that for various reasons, are more vulnerable to addiction. Minority group members are particularly impacted by the adverse effects of drugs and alcohol. It is well documented that Native Americans have the highest prevalence of alcohol problems among all U.S. population groups, while other medical data shows that Blacks and Hispanics are disproportionate users of dangerous drugs, that is, those drugs that are more likely to cause adverse health consequences or death.

Years of struggling with the Nation's drug abuse problem has clearly demonstrated that an effective response can not be limited to stemming the drug supply nor treatment for its casualties but must also include an effective prevention component that can find ways to address and prevent potential substance abuse problems before they negatively impact on both individuals and families.

The Congress responded to the continued rise of illicit drug use during the early to mid 1980s with the establishment of the Office for Substance Abuse Prevention (OSAP). The Anti-Drug Abuse Act of 1986 mandated that OSAP initiate programs to focus on reaching "high risk youth", establish a clearinghouse, and provide technical assistance to communities in alcohol and other drug abuse prevention. Subsequent drug abuse legislation strengthened OSAP's portfolio by adding programs to: directly address the problem of drug abuse involving pregnant women and their infants; initiate a program working through the States (the Community Youth Activity Program) that would assure State inclusion in the national prevention program; enhance the building of a Federal prevention network through conferences and workshops; and, begin the establishment of a national training system to assure competent personnel to staff the new and expanding programs.

Programs added with the FY 1990 appropriation broadened and balanced OSAP's national program by establishing a major new systems-oriented Community Partnership program, providing an innovative cooperative agreement program for communities to develop population specific drug abuse messages, and mandating the development of a national prevention evaluation program to provide an analytical look at where we are going, how we are progressing, and what we are learning nationally.

What has emerged is a national focus for a comprehensive, balanced, multi-faceted, long-term approach to substance abuse prevention. OSAP prevention services demonstrations are well balanced between the client-oriented programs of the 1986 and

1988 Acts (High Risk Youth Grants and Pregnant/Post Partum Women and Infants Grants) and the system-oriented Community Partnership program of the FY 1990 appropriation. A national training system ensures skilled personnel in the various prevention and treatment programs that are supported by OSAP and/or ADAMHA programs. The National Clearinghouse for Alcohol and Drug Abuse Information and the communication cooperative agreements provide knowledge dissemination and assure that the general public is kept well informed about substance abuse prevention. Conference grants allow for information sharing and networking opportunity for those working in this relatively new field.

In all of its program efforts, OSAP promotes the concept of no use of any illegal drug and no illegal use of alcohol or other legal drugs. OSAP bases its prevention work on several premises:

- o the earlier prevention is started in a person's life cycle, the more likely its success;
- o intervene as early as possible
- o focus on alcohol as well as other drugs
- o emphasize family-focused programs
- o recognize cultural diversity and sensitivity
- o provide a continuum of care and comprehensiveness
- o encourage community involvement

Examples of efforts undertaken by the OSAP program include: the development of numerous media campaigns including the first national media campaign aimed specifically at preventing alcohol and other drug use among Hispanic youth. This campaign includes a new bilingual (English/Spanish) set of materials in response to the Hispanic Community's expressed desire for culturally sensitive and linguistically appropriate prevention materials.

In another OSAP sponsored program, more than 1,200 children and 800 parents are finding effective help for their drug-related problems through SUPER II, an early intervention program run by the Metropolitan Atlanta Council on Alcohol and Drugs (MACAD) and funded under a 3-year High Risk Youth grant. Evaluation of the MACAD program found that drug use by the program's participants showed a dramatic decrease.

OSAP has also taken initiatives to insure there are adequately skilled substance abuse prevention personnel. One such initiative will provide for fifty-five "Training of Trainer Programs" over three years and will train over 1,200 people who will in turn be qualified to provide training to other practitioners in the field. Yet another OSAP accomplishment is the development of the "Framework," which attempts to state as clearly and succinctly as possible the parameters to guide any community in developing an effective alcohol and other drug abuse prevention system.

OSAP has begun the mandated National Evaluation of Prevention and Education Approaches to Reduce Drug Abuse. Under Section 3522 of

the Anti-Drug Abuse Act, OSAP was mandated to undertake a structured national evaluation of the different approaches utilized across the Nation to reduce drug abuse. It further required that a report based on these evaluations be submitted no later than one year after the effective date of the legislation.

OSAP has created a three-phase strategy aimed at implementing this mandate in a comprehensive manner. Phase I includes the development of a compendium and analysis of the drug reduction, prevention, and education projects, as well as reports on the findings of those projects with an evaluation component. Information from this database is anticipated to provide a baseline for the proposed activities of Phase II--the development of a feasible evaluation design that will provide both quantitative and qualitative information on the Nation's education and prevention drug reduction projects. Phase III will entail the implementation of the proposed structured evaluation.

Office for Treatment Improvement

The Office for Treatment Improvement (OTI), created in January of 1990, is responsible for improving the Nation's drug treatment system and has oversight of the Alcohol, Drug Abuse and Mental Health Services (ADMS) and the Mental Health Services for the Homeless (MHS) Block Grants. OTI provides grant funds to States and local treatment providers to assist them with the improvement of their drug treatment programs. OTI works closely with the research agencies including the National Institute on Drug Abuse, the National Institute on Alcohol Abuse and Alcoholism, and the National Institute of Mental Health.

OTI was created to ensure transfer of the latest treatment technology to the public sector, illustrate "what works" in addiction treatment and to strengthen the capabilities of the publicly funded treatment infrastructure (e.g. enhance the number of qualified treatment staff, improve state planning and management capabilities). Critical areas of knowledge development concerning drug treatment include: efficiency and effectiveness of drug treatment modalities, provider settings and staff structures; organization, delivery, impact and quality of drug abuse treatment; cost of treatment services; accessibility of treatment services; and what treatment components work for which patients.

Two major goals of OTI are:

Goal 1: Enhance Coordination of Services

- Primary and preventive medical care
- AIDS prevention and treatment
- Psychiatric and psychological services
- Family counseling
- Life and social skills
- Welfare/food/shelter
- Vocational rehabilitation
- Educational/cognitive skills

Goal 2: Expand/Improve Treatment for At-Risk Populations

- Pregnant and Post-partum Women, their Infants and Children
- Adolescents
- Racial and Ethnic Minorities
- Residents of Public Housing and the Homeless
- Co-morbid Populations
- Correctional Populations

Capacity and Quality Enhancement

Treatment improvement implies both increased access and increased quality of service provision. The ADMS block grant provides both the single largest funding source for capacity expansion and a unique opportunity to guide and monitor treatment service delivery nationwide. The ADMS block grant is the best method by

which to guide and monitor addiction treatment services on a national scale. The Block Grant allows States the latitude to design solutions to location-specific treatment problems. OTI is committed to the development of systems that will allow improved State accountability in use of both the block grant and State/local resources.

Demonstration Programs and Special Initiatives

OTI implemented several demonstration projects in FY 1990, including: 1) the Target Cities program, 2) the Critical Populations program, 3) Treatment in Criminal Justice Settings, and 4) the Waiting Period Reduction Grant program. All OTI demonstration programs emphasize HIV/AIDS testing, counseling, prevention, and treatment as requisite components of a comprehensive care milieu.

Treatment Grants to Crisis Areas (Target Cities)

The primary goal of this program is to implement overall systemic improvements in metropolitan settings. This is a competitive grant program, however; the State has to prove that there is a high incidence of drug abuse and a chronic need for treatment improvement in the jurisdiction. Also, States are required to provide assurance of support during and after the period of Federal funding for this program.

Establishment of central intake, assessment and referral systems are a mandatory component of the program. Central intakes are to provide a broad array of testing services, including HIV antibody testing for all persons who present for treatment who are also at-risk of the HIV. Central intakes facilitate better treatment-patient matching and more rapid referral to treatment services. Their presence in urban areas should facilitate a solution to existing maldistribution of capacity and ensure reduction in the average waiting period for treatment.

Critical Populations Grants Program

The three year demonstrations are for treatment program/treatment system enhancements geared toward the following critical populations: 1) adolescents, 2) racial and ethnic minorities, and 3) residents of public housing. Homeless and patient subgroups with a high incidence of physical and mental illnesses, in addition to substance abuse disorders, will receive special attention under this program.

Under the auspices of this program, OTI funded the following program components: 1) enhanced outreach methods, 2) provision of on-site primary medical care and provision of, or establishment of formal arrangements for acute medical care, 3) testing for HIV/AIDS and sexually transmitted diseases, 4) staff training, 5) health education (includes AIDS education), 6) life skills counseling, 7) educational and vocational

counseling, 8) enhanced aftercare (to include drug-free cooperative housing post-residential treatment), 9) psychological and psychiatric services for patients with mental disorders, and 10) facility improvements.

Criminal Justice Grant Programs

OTI established demonstration grants in FY 1990 for treatment programs in criminal justice settings. Funding is for three year demonstrations for treatment program enhancements that are geared toward substance abusers in the criminal justice system. The demonstrations are in one or more of the following areas:

1) improved coordination of all facets of the criminal justice system (i.e. courts, jails, social services, and treatment systems), 2) policies and procedures for deferring arrestees into treatment in lieu of incarceration, 3) on-site provision of drug treatment services in a jail or prison setting, 4) primary medical care (including HIV/AIDS testing, counseling and prevention), and 5) educational counseling and job training services.

The Waiting Period Reduction Grant Program

Under this program, grants are available for treatment programs that have verifiable "waiting lists." The Waiting List grant program was designed solely to expand treatment capacity in areas where patient demand clearly exceeds availability of service. Under the auspices of this program, special preference is being given to applicants in FY 1991 that propose to provide services designed to address the specific needs of perinatal women. HIV/AIDS counseling, testing, and prevention services are a requisite for this population. This program is designed to provide the seed money to establish new treatment slots. In order to be eligible to apply for this program, applicants must provide assurance of future funding from non-Federal sources following the period covered by the Federal grant award.

Demonstration Programs Planned for FY 1991

In FY 1991, OTI will conduct two Treatment Campus demonstrations. Under this program, cooperative agreements will be established between States and NIDA/OTI for establishment of treatment "campuses." Each campus will consist of five to eight distinct service providers that occupy a [large] common facility. Central intake, patient assessment, referral, and program evaluation will be on-site. Treatment providers will jointly utilize central intake, food, recreational and commissary facilities but will otherwise be autonomous. The total patient population on any given campus will be at-or-near 500. The goal of the project is three-fold: 1) to enhance treatment capacity, 2) to improve the quality of treatment, especially through provision of primary medical care and HIV/AIDS testing, counseling and prevention, and 3) to create a controlled environment for assessment and

evaluation of the efficacy of differing approaches to treatment service provision.

Other OTI Initiatives

OTI has a number of special initiatives and planning efforts underway, all of which are designed to improve treatment service delivery.

The Primary Care Provider/Substance Abuse Linkage Initiative

This initiative is designed to strengthen the linkages between the primary health care and the alcohol, drug abuse, and mental health (ADM) treatment systems. The Linkage Initiative consists of incremental phases, each of which builds upon the information and experience gained upon the previous component. The Initiative begins with regional work groups of medical and ADM consortia and practitioners. These workgroups will identify major issues, barriers and constraints that interfere with close and essential collaboration between primary medical care and ADM providers. The last component of the Initiative is a Federal demonstration grant program that will focus upon the delivery of primary health care services in ADM treatment environments. HIV/AIDS testing, counseling, prevention and treatment will constitute a requisite component of this program.

Treatment Guideline Development

OTI is working to develop drug treatment guidelines for publication and distribution to State and local governments. Guidelines are presently being developed for the treatment of all critical populations, for patients who suffer from mental illness in addition to addictive disorders, and for patients in criminal justice settings. HIV/AIDS testing, counseling, prevention and treatment will be covered by all OTI guidelines. Separately, OTI is working in concert with NIDA to develop treatment guidelines for programs that utilize methadone as a pharmacotherapy. These guidelines will emphasize methadone as one adjunct to a comprehensive treatment milieu that emphasizes provision of primary medical care and other health and human services, in addition to basic substance abuse counseling, educational and job training services.

Treatment Staff Training and Development

OTI will be implementing a nationwide counselor training effort in FY 1991 as part of the Office for Substance Abuse Prevention's (OSAP) National Training System.

In FY 1990, OTI implemented a pilot program designed to expose minority medical students to addiction treatment environments through participation in summer fellowships in addiction treatment programs. As a result of the success of the pilot project, OTI intends to expand the fellowship process in FY 1991

through a collaborative effort with the ADAMHA research institutes.

The D.C. Initiative

OTI is collaborating with NIDA to implement a treatment improvement project in the District of Columbia. Under this effort, NIDA grants for establishment of central intake and referral services, and two outpatient programs will be coupled with OTI resources for creation of a residential treatment facility, aftercare and other treatment program enhancements. The residential component is to emphasize provision of primary medical care, testing for HIV infection, HIV/AIDS counseling and prevention and provision of prophylactic medications. The primary emphasis of this program is: 1) treatment capacity expansion for the District of Columbia, and 2) treatment research.

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HEALTH RESOURCES AND SERVICES ADMINISTRATION
Bureau of Health Professions

Substance Abuse

In FY 1990, a number of the Bureau's grant programs indicated specific emphasis on training their students in the intervention of health care problems associated with drug abuse, alcohol abuse and alcoholism.

Twelve Area Health Education Center projects were funded for their programming activities in the area of substance abuse. A total of \$110,150 was awarded for these activities, and the programs are estimated to impact 5,209 individuals. Health professions students and medical residents will be exposed to the treatment of health problems and patient education in this area.

One AIDS Education and Training Center project reported specific training emphasis on the association of alcohol abuse and the HIV/AIDS epidemic.

The University of Washington received \$13,922 for the development of a substance abuse component under its Health Education and Training Center project. It is expected that 70 individuals will benefit from this training.

Among the Family Medicine programs, 5 Predoctoral Training program grantees have educational components on substance abuse, impacting 93 students. Also under section 786(a) authority, 13 graduate training program grantees indicated training in this area, which would benefit 130 residents. The Maine/Dartmouth residency program was awarded \$61,505 specifically for their development of substance abuse curriculum.

Fifteen General Internal Medicine/General Pediatrics Residency Training programs indicated that residents would receive training in substance abuse problems, impacting approximately 78 individuals. No funds were requested specifically for this purpose. Also, 3 grantees under the Faculty Development program provide training in this area for 9 faculty.

An estimated 841 physician assistant trainees among 18 grantee programs will be exposed to curriculum designed to prepare these individuals to recognize health problems associated with substance abuse. Funds in the amount of \$11,230 were awarded to the PA program at Western Michigan University for the improvement of their substance abuse curriculum.

The Bureau also assisted in the support of three workshops focused on drug and substance abuse. The purpose of the consortium was to develop a national plan for the education of RN's and nursing students about alcohol and drug abuse.

Three Preventive Medicine Residency grantees indicated that seven individuals will benefit from training in this area.

A substance abuse component will be integrated into 4 of the faculty training projects in geriatric medicine and dentistry, impacting 19 faculty fellows.

INDIAN HEALTH SERVICE

Alcoholism and Substance Abuse Services

Since 1978, the alcoholism age adjusted death rate among American Indians/Alaska Natives (AI/AN) has declined by approximately 52 percent. This improvement can be attributed to several factors:

- the continued training of Indian Health Service (IHS) and Bureau of Indian Affairs (BIA) staff, community members, and IHS Primary Care Providers;
- the increased number of alcoholism and substance abuse programs from 36 to over 309; and, most importantly, AI/AN communities are taking responsibility for their own wellness;
- continued emphasis on the concepts of wellness, health promotion/disease prevention.

Revision of the Chemical Dependency Management Information System will be completed in Fiscal Year (FY) 1991. Implementation of the system on a service-wide basis will begin in FY 1991 to better manage all inpatient, outpatient, education and prevention activities. The revised system will allow tribes direct access to their data for immediate recall and oversight. Local management will be enhanced.

Anti-Drug Abuse Activities (Public Law 99-570 and Public Law 100-690)

Four Youth Regional Treatment Centers (RTCs) authorized by Public Law (P.L.) 99-570 are renovated and operational as of November 1990. These include Albuquerque, Oklahoma City, Nashville, and Navajo Areas. Two facilities located in Fairbanks and Sitka of the Alaska Area and one facility in the Portland Area are operational but require renovation. Two other IHS Areas (Phoenix and Aberdeen) are renovating facilities and are expected to become operational in FY 1992. The remaining Areas are providing inpatient chemical dependency treatment through contracts pending completion of their plan for RTCs. Plans are currently being developed for each Area to assure access to inpatient treatment by youth. Resources from the existing IHS alcoholism program (P.L.94-437) augment the adolescent alcoholism and substance abuse program by providing for a broader range of comprehensive services.

Expanded community education and training activities will continue to be provided for Indian leaders, community members, BIA and IHS staff. It is projected that more than 1,000 health care providers will receive training in alcohol and other drug abuse prevention and treatment in FY 1991.

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Alcohol continues to be the drug of choice in Indian Country. However, alcohol and poly-drug use, specifically cannabis, cocaine, and opiates, are increasing among AI/AN adults and adolescents. It is projected in FY 1991 there will be 1679 initial contacts related solely to drug use.

In FY 1991, adult and youth community rehabilitation, aftercare, and follow-up services will continue to be developed. These services enhance the basic alcoholism and substance abuse program. The alcoholism and substance abuse programs are projected to provide 373,443 outpatient visits and 213,657 inpatient days in FY 1991. In FY 1992, it is projected 386,633 outpatient visits and 224,104 inpatient days will be provided.

The IHS will continue to work with the AI/AN communities to integrate the treatment, education, and prevention of alcoholism and substance abuse into the health delivery system. It is projected 343,241 education and prevention contacts will be provided in FY 1991 and 355,253 contacts in FY 1992.

CENTERS FOR DISEASE CONTROL

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SUBSTANCE ABUSE

HIV prevention among injecting drug users (IDUs) is accomplished in several ways through programs funded by CDC. For example, community activities are often conducted by former addicts providing education, risk reduction messages, and treatment referral to IDUs and their sex/needle-sharing partners. These activities also include street outreach programs. Support for these activities is provided through cooperative agreements with State and local health departments and the direct funding of minority and other CBOs.

CDC has developed a model joint plan for use by State/local health departments and State drug agencies to assist them in providing comprehensive HIV/STD/TB prevention programs in drug treatment centers.

In 1991, an increase of \$3,938,000 will be used to assess the effectiveness of street outreach in reducing high-risk behaviors associated with HIV infection in IDUs and their sex/needle-sharing partners. HIV counseling and testing services will continue to be provided to IDUs and their sex/needle-sharing partners in drug treatment centers, public health clinics (i.e., STD, women's health, and TB clinics), and alternate test sites.

FOOD AND DRUG ADMINISTRATION
SUBSTANCE ABUSE PROGRAM

As part of its regulatory responsibilities, FDA maintains an ongoing program of monitoring narcotic treatment centers to assure their compliance with established standards related to DEA registration. In addition, FDA investigates the abusive use of approved drugs, such as steroids, and non-approved look-alike drugs.

FDA reviews applications from hospitals and narcotic treatment programs for use of methadone in the treatment of narcotic addiction and approves those that comply with narcotic treatment standards promulgated by FDA and the National Institute of Drug Abuse. FDA monitors narcotic treatment programs to determine compliance with the narcotic treatment standards, initiating procedures to suspend or to revoke the DEA registration of centers which fail to comply with the standards.

The FDA methadone monitoring program has been expanded to include a more positive approach as well. In site visits to the methadone treatment centers, FDA inspectors are identifying specific areas which are in need of assistance to improve operations and assure compliance. Areas targeted include:

- o the availability and provision of appropriate counseling and support services;
- o the conduct of proper screening procedures to prevent the provision of treatment services to non-addictive persons and pregnant women;
- o the development and administration of proper dose regimens under medical supervision required for satisfactory detoxification; and,
- o the conduct of appropriate client interviews by medical personnel to assess degree of addiction and document personal history.

FDA remains very concerned about continuing illegal use of look-alike and approved drugs, especially steroids. Penalties for illegal distribution of these drugs were increased in severity and FDA's investigational activities in this regard have been strengthened in an effort to curb this abuse. Comprehensive investigation into the illegal use of anabolic steroids is an ongoing effort of FDA and public education and outreach efforts targeted at users was increased as a critical method for reducing this abuse.

OFFICE OF HUMAN DEVELOPMENT SERVICES

Substance Abuse

- The Drug Education and Prevention Program for Youth Gangs is intended to reduce and prevent the participation of youth gangs in illicit drug activities. Activities are supported to encourage youth involvement in lawful activities, to educate youth about problems associated with drug abuse, to support local law enforcement in educational outreach, to inform gang members and their families concerning drug treatment, to facilitate cooperative efforts among federal, State and local agencies, particularly schools to prevent youth from becoming involved with gangs that commit drug-related crimes, and to facilitate coordination and cooperation among local education, juvenile justice, employment and social service agencies, drug abuse treatment and referral and rehabilitation programs. In fiscal year 1990, 72 discretionary grants were awarded. In addition, awards were also made to support technical assistance, monitoring and evaluation. Continuation and expansion of these efforts is anticipated in fiscal years 1991 and 1992.
 - The Drug Education and Prevention Program for Runaway and Homeless Youth is designed to reduce and prevent the illicit use of drugs by youth who run away from home or who are homeless. Support is provided for public and private non-profit organizations for research, demonstration and service projects-- counseling, community education, training and information--and other activities to increase the availability and coordination of local services to discourage drug abuse. Priority is given to agencies experienced in services for runaway and homeless youth.
- During fiscal year 1989, competitive demonstration grants were made to 104 agencies and organizations representing 35 States and the District of Columbia, in addition to technical assistance, monitoring and evaluation efforts. In fiscal year 1990 the number of discretionary grants increased to 164. It is anticipated that these activities and those related to will be continued and expanded in fiscal years 1991 and 1992.
- The Abandoned Infants Assistance program provides financial support to public and non-profit private entities to develop, implement, and operate demonstration projects to prevent the abandonment of infants and young children, particularly those who have been exposed to HIV, AIDS or maternal drug abuse. (Note: There is a significant overlap between those who are drug exposed and those who may be HIV positive. The total funding for this program has been included in substance abuse related expenditures.)

Substance Abuse, page 2

In fiscal year 1990, 17 model comprehensive service projects to organize or augment a program of comprehensive services-- foster family care, case management, family support services, respite and crisis intervention, and counseling; five cross-disciplinary training projects; two resource development and coordination projects to assist States and localities to develop innovative approaches for use of funds obtained from different funding sources for coordinated services; and five coordinated early intervention for HIV positive children at high risk for developmental disabilities were funded to improve services and prevent abandonment. In addition, under an Interagency Agreement with the Bureau of Maternal and Child Health, supplements were made to 12 Pediatric AIDS Demonstration Centers to augment services to prevent the abandonment of infants or young children. These efforts will be continued in fiscal years 1991 and 1992. In addition, it is anticipated that two resource centers will be funded for technical assistance, monitoring, evaluation, and other services to grantees.

- The Emergency Child Abuse and Prevention Services grant program is in its first year. It will provide support for services to children whose parents are substance abusers in order to prevent child abuse and/or neglect. Applicants must provide (1) assurances that the State and local agencies in the geographic area to be served are experiencing substantial increases in service demands which cannot be satisfied with existing resources, (2) identify the responsible agency(ies) to be involved in the use of funds, (3) describe the emergency situations faced by children of substance abusers, (4) a plan for improving the delivery of such services; and (5) assurances that services will be provided in a comprehensive, multi-disciplinary, and coordinated manner. It is estimated that approximately 100 projects will be initiated in fiscal year 1991 and continued in fiscal year 1992.
- The Temporary Child Care for Children with Disabilities and Chronically Ill Children is meant to alleviate social, economic, and financial stress in families with disabled or chronically ill children. In four of thirteen projects funded in fiscal year 1990 children in drug abusing families were referenced among those to be served. Some of the remaining projects might also serve such families.
- The Crisis Nurseries program provides for temporary emergency services and care for children to prevent abuse or neglect. In seven of the nine projects funded under this program in fiscal year 1990, children in drug abusing homes were specifically referenced among those to be served.

Substance Abuse, page 3

- States may also use funds provided under the Social Services Block Grant (SSBG), Child Welfare State Grants, Child Abuse and Neglect State Grants, and Family Violence State Grants for substance abuse related activities. However, States are not required to report on the use of these Federal funds in such manner as to permit estimates of the amounts used in connection with substance abuse. Similarly, substantial Federal outlays are used to support children who are placed in foster care, a condition frequently associated with substance abuse in the home.

H-1

Department of Health and Human Services
National Support for Performance of Medical and Health-Related R&D, by Source of Funds
Fiscal Years 1969-1990 *

(Millions of Dollars)

Source of Funds	1969	1970	1971	1972	1973	1975	1975	1976	1977	1978	1979
Total	\$2,785	\$2,847	\$3,168	\$3,536	\$3,750	\$4,443	\$4,701	\$5,107	\$5,568	\$6,262	\$7,133
Government	1,818	1,837	2,075	2,375	2,470	3,008	3,118	3,371	3,734	4,227	4,786
Federal	1,674	1,667	4,970	5,399	6,087	6,791	6,895	7,847	8,425	9,230	9,321
NIH	(893)	(873)	(1,039)	(1,271)	(1,323)	(1,737)	(1,880)	(1,060)	(2,280)	(2,581)	(2,953)
State & local	144	170	198	228	245	254	286	312	338	416	465
Industry	754	795	860	934	1,048	1,183	1,319	1,469	1,614	1,800	2,093
Private nonprofit	213	215	233	227	232	252	264	267	220	236	254
Foundations	69	69	83	77	75	79	86	76	71	65	60
Voluntary health											
agencies	61	61	63	63	70	84	85	94	102	113	129
Howard Hughes											
Med. Inst.	0	0	0	0	0	0	0	0	0	0	0
Other	83	85	87	87	87	89	93	97	47	57	66

* Excludes research training and construction. Includes U.S. funded health R&D support spent abroad. Revised data for 1970 forward.

Note: Federal data obtained via an interagency survey conducted by the National Institutes of Health. Estimates for State and local governments include awards made by governmental agencies as well as appropriations made to educational institutions for the performance of health R&D. Industry sector includes data for the pharmaceutical, medical supply, biomedical engineering, and biotechnology industries. The non-industrial private sector covers philanthropic foundations, voluntary health agencies, the Howard Hughes Medical Institute, and other private contributors for the support of health R&D.

Department of Health and Human Services
National Support for Performance of Medical and Health-Related R&D, by Source of Funds
Fiscal Years 1969-1990 *

(Millions of Dollars)

Source of Funds	1980	1981	1982	1983	1984	1985	1986	1987	1988	1989 (est.)	1990 (proj.)
Total	\$7,953	\$8,723	\$9,540	\$10,748	\$12,136	\$13,502	\$14,823	\$16,832	\$18,847	\$20,781	\$22,567
Government	5,203	5,413	5,605	6,112	6,880	7,664	7,921	8,992	9,697	10,569	11,298
Federal	4,723	4,848	4,970	5,399	6,087	6,791	6,895	7,847	8,425	9,230	9,856
NIH	(3,182)	(3,333)	(3,433)	(3,789)	(4,257)	(4,828)	(5,005)	(5,852)	(6,292)	(6,778)	(7,141)
State & local	480	564	634	712	793	874	1,026	1,145	1,272	1,339	1,442
Industry	2,459	2,998	3,593	4,205	4,765	5,325	6,188	7,115	8,406	9,433	10,442
Private nonprofit	292	312	343	431	491	486	714	725	744	779	827
Foundations	54	52	44	82	113	89	83	115	97	82	69
Voluntary health agencies	146	161	178	188	187	213	238	257	287	310	334
Howard Hughes											
Med. Inst.	18	20	25	54	79	51	247	183	179	197	220
Other	73	79	96	107	112	133	146	170	181	191	205

* Excludes research training and construction. Includes U.S. funded health R&D support spent abroad. Revised data for 1970 forward.

Note: Federal data obtained via an interagency survey conducted by the National Institutes of Health. Estimates for State and local governments include awards made by governmental agencies as well as appropriations made to educational institutions for the performance of health R&D. Industry sector includes data for the pharmaceutical, medical supply, biomedical engineering, and biotechnology industries. The non-industrial private sector covers philanthropic foundations, voluntary health agencies, the Howard Hughes Medical Institute, and other private contributors for the support of health R&D.

History of Congressional Action on Budget Requests 1/
for National Institutes of Health Institutes and Research Divisions

	Budget Estimate to Congress	Appropriation		Budget Estimate to Congress	Appropriation
1933.....	\$48,000	\$48,000	1975.....	\$1,785,922,000	\$2,043,721,000
1934.....	54,775	54,775	1976.....	2,349,413,000 17/	2,627,845,000
1935.....	50,000	50,000	1977.....	2,088,179,000	2,424,510,000
1936.....	64,000	64,000	1978.....	2,456,104,000	2,720,767,000 18/
1937.....	64,000	64,000	1979.....	2,794,623,000	3,097,138,000 19/
1938.....	464,000	464,000	1980.....	3,111,391,000	3,360,670,000
1939.....	515,000	515,000	1981.....	3,432,146,000	3,490,459,000 20/
1940.....	587,750	707,000	1982.....	3,239,274,000 21/	3,563,324,000 22/
1941.....	712,120	711,000	1983.....	3,660,945,000	3,929,843,000 22/
1942.....	705,000	700,000	1984.....	3,980,856,000	4,374,768,000 23/
1943.....	1,278,270	1,278,270	1985.....	4,476,524,000	5,033,515,000
1944.....	1,291,000	2,555,020	1986.....	4,748,750,000	5,308,754,000 24/
1945.....	2,835,000	2,835,000	1987.....	4,936,157,000	6,031,964,000 25/
1946.....	2,078,000	3,414,700	1988.....	5,407,785,000 26/	6,666,693,000
1947.....	10,799,500	8,125,448 2/	1989.....	6,407,168,000	7,245,836,000 27/
1948.....	22,403,000	28,876,000	1990.....	6,776,727,000 28/	7,443,452,000 29/
1949.....	45,701,460	37,668,000	1991.....	7,668,495,000	7,918,993,000
1950.....	40,567,000	50,167,000	1992.....	8,475,031,000	
1951.....	49,845,000	47,334,750 3/			
1952.....	53,386,000	52,447,291			
1953.....	55,005,000	59,030,750			
1954.....	56,340,000	71,153,000			
1955.....	71,128,000 4/	81,268,000			
1956.....	90,023,000 5/	98,458,000			
1957.....	126,725,000 7/	183,007,000			
1958.....	190,183,000	211,183,000			
1959.....	211,814,000	294,383,000			
1960.....	294,279,000	400,000,000			
1961.....	400,000,000	560,000,000 8/			
1962.....	583,000,000	738,335,000 9/			
1963.....	780,400,000	880,800,000			
1964.....	930,454,000	918,454,000			
1965.....	956,492,000	965,992,000			
1966.....	1,105,006,000 10/	1,138,406,000			
1967.....	1,231,764,000	1,306,983,000			
1968.....	1,152,250,000 11/	1,143,424,000			
1969.....	1,188,293,000	1,100,092,000			
1970.....	1,064,870,000 12/	1,122,718,000 13/			
1971.....	1,099,249,000	1,196,249,000			
1972.....	1,333,916,000 14/	1,476,046,000			
1973.....	1,483,982,000 15/	1,713,455,000			
1974.....	1,531,776,000	1,744,554,000 16/			

NOTE: Not all amounts on this table are comparable from year to year because of changes in the content of the appropriations.

- 1/ This table excludes the National Library of Medicine, Office of the Director, Buildings and Facilities.
- 2/ Includes \$386,500 in transfers.
- 3/ Not less than \$3,000,000 was earmarked for liquidating cash; an additional \$1,175,000 was used for that purpose.
- 4/ Excludes \$3,216,250 rescinded.
- 5/ Excludes \$131,000 for Gorgas Memorial Laboratory.
- 6/ Excludes \$147,000 for Gorgas Memorial Laboratory.
- 7/ Includes \$90,500 in transfers.
- 8/ Includes \$200,000 transfer from other appropriations.
- 9/ Includes \$12,129,000 for construction of mental health-neurology research facility.
- 10/ Includes \$1,000,000 for planning for a gerontological research facility; and \$750,000 for modernization at the Rocky Mountain Laboratory, Hamilton, Montana.
- 11/ Includes 25,000,000 for Regional Medical Programs, \$19,700,000 for Mental Health Staffing, and \$20,250,000 for Heart Disease, Cancer and Stroke.
- 12/ Includes \$246,741,000 for National Institute of Mental Health. Includes \$20,616,000 for Environmental Health Sciences.
- 13/ Excludes \$7,093,000 for the Office of the Director, NIH.
- 14/ Includes \$1,348,200 supplemental.
- 15/ Includes \$142,075,000 in supplementals.
- 16/ Excludes OBS. Request reflects amendment.
- 17/ House Allowance reflects maximum authorized. Reflects P.L. 93-192.
- 18/ Request reflects amendment requested for 1976 in 1977 budget submission. Estimate and appropriation includes the Transition Quarter (15 month period).
- 19/ Continuing Resolution was Conference Allowance, includes supplemental of \$17,834,000.
- 20/ Includes Continuing Resolution for items not considered in P.L. 95-482.
- 21/ Reflects rescission of \$46,959,000 authorized under P.L. 97-12.
- 22/ Reflects the September amendment, the original request was \$3,680,994,000.
- 23/ Continuing Resolution.
- 24/ Includes Continuing Resolution for items not considered in P.L. 98-139.
- 25/ Reflects transfer of \$4,500,000 to DHHS from NCI for the Mary Babb Randolph Cancer Center and an administrative reduction of \$3,000,000.
- 26/ Includes supplemental of \$2,250,000.

27/ Does not include administrative reduction of \$86,947,000 or procurement reduction of \$6,684,000.

28/ Excludes \$752,670,000 for AIDS research proposed for consolidation in OASH.

29/ Includes \$752,670,000 for AIDS research.

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Alcohol, Drug Abuse, and Mental Health Administration

History of Congressional Action of Budget Requests.

Year	Budget Estimate to Congress	Appropriation
1947	4,478,000	0
1948	5,108,000	4,250,000
1949	11,501,000	9,128,000
1950	9,662,000	10,862,000
1951	7,569,000	7,130,000
1952	10,022,000	9,988,773
1953	10,917,000	10,895,000
1954	9,817,000	12,095,000
1955	12,640,000	14,147,000
1956	17,751,000	18,001,000
1957	21,749,000	35,197,000
1958	35,217,000	39,217,000
1959	37,788,000	52,419,000
1960	52,384,000	68,090,000
1961	67,563,000	100,900,000
1962	88,324,000	108,876,000
1963	126,899,000	143,599,000
1964	190,096,000	183,288,000
1965	224,085,000	222,932,000
1966	278,669,000	282,669,000
1967	305,115,000	315,619,000
1968	346,909,000	346,909,000
1969	364,939,000	350,439,000
1970	357,904,000	360,302,000
1971	346,656,000	389,238,000
1972	500,263,000	613,013,000
1973	603,719,000	803,823,000
1974	645,533,000	815,975,000
1975	692,190,000	795,636,000
1976	783,482,000	930,765,000
1977	645,509,000	885,571,000
1978	881,293,000	941,668,000
1979	1,002,871,000	1,025,085,000
1980	1,115,768,000	1,111,146,000
1981	1,092,724,000	1,024,734,000
1982	821,823,000	860,178,000
1983	372,682,000	885,849,000
1984	420,570,000	915,759,000
1985	421,250,000	923,626,000
1986	886,194,000	927,199,000
1987	1,123,240,000	1,375,065,000
1988	1,042,873,000	1,373,727,000
1989	1,504,413,000	1,845,712,000
1990	2,038,716,000	2,625,938,000
1991	2,831,511,000	2,935,763,000
1992	3,048,328,000	---

DEPARTMENT OF HEALTH AND HUMAN SERVICES

PUBLIC HEALTH SERVICE

Requests in the FY 1992 Budget for Which Legislative

Authority has Expired or is Due to Expire on September 30, 1991
(Dollars in thousands)

Appropriation/ Program	Expiring Authorization	Amounts Included in President's Budget
H.P Student Assistance: Exceptional Fin. Need	PHS Act, Sec. 758	10,400
Disadvantaged Assistance	PHS Act, Sec. 787	32,841
Nurse Education Opportunities	PHS Act, Sec. 827	4,160
AIDS: Education Training Centers	PHS Act, Secs. 788 (a)-(e) & 301	17,029

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control

Requests in the FY 1992 Budget for Which Legislative
Authority has Expired or is Due to Expire on September 30, 1991

(Dollars in thousands)

APPROPRIATION / PROGRAM	EXPIRING AUTHORIZATION	AMOUNTS INCLUDED IN PRESIDENT'S BUDGET
Disease Control, Research, and Training:		
-- Preventive Health and Health Services BG	Public Health Service Act (PHSA) Title 19 Section 1901 (a)	\$101,503 1/
-- Prevention Centers	PHSA Section 1706 (e)	\$3,949 1/
-- Sexually Transmitted Disease Grants	PHSA Section 318D (1)	\$77,638
-- Lead Poisoning Prev.	PHSA 317 (a)	\$14,949
1/ Authorization expires September 30, 1991. An extension is pending.		

DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health

Requests in the FY 1992 Budget for Which Legislative
Authority has Expired or is Due to Expire on September 30, 1991

(Dollars in thousands)

APPROPRIATION / PROGRAM	EXPIRING AUTHORIZATION	AMOUNTS INCLUDED IN PRESIDENT'S BUDGET
National Cancer Institute	Title IV, Part A, Section 408 (a) (1) (A) of PHS Act Section 408, (a) (1) (B) of PHS Act	\$1,682,774 \$85,869
National Heart, Lung and Blood Institute	Title IV, Parts B&C of PHS Act	\$1,162,725
National Research Service Awards	Section 487 of PHS Act	\$314,638
Medical Library Assistance	Title IV, Part D, Section 469-477 of PHS Act	\$14,691
Biotechnology Information	Title IV, Part D, Section 478 of PHS Act	\$10,466

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Alcohol, Drug Abuse, and Mental Health Administration

Requests in the FY 1992 Budget for Which Legislative
Authority has Expired or is Due to Expire on September 30, 1991

(Dollars in thousands)

APPROPRIATION / PROGRAM	EXPIRING AUTHORIZATION	AMOUNTS INCLUDED IN PRESIDENT'S BUDGET
Instrumentation Grants	PHSA Section 501	\$2,443
Demonstrations/Drugs	PHSA Section 509G	\$118,505
Demos/Substance Abuse	PHSA Section 508(d)	\$239,357
Clinical Training	PHSA Section 508(d)	\$25,986
Program Management and Support (OSAP)	PHSA Section 508(d)	\$16,237
Treatment Improvement Programs	PHSA Section 509G	\$119,246
ADMS Block Grant	PHSA Section 1911(a)	\$1,268,670
Research Training	PHSA Section 487	\$38,387

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DEPARTMENT OF HEALTH AND HUMAN SERVICES
PUBLIC HEALTH SERVICE
ASSISTANT SECRETARY FOR HEALTH

Requests in the FY 1992 Budget for Which Legislative
Authority has Expired or is Due to Expire on September 30, 1991

(Dollars in thousands)

APPROPRIATION/PROGRAM	EXPIRING AUTHORIZATION	AMOUNTS INCLUDED IN PRESIDENT'S BUDGET
Office of the Assistant Secretary for Health:		
Adolescent Family Life	PHSA Title XX	\$12,000
Disease Prevention & Health Promotion	PHSA Title XVII	4,577

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Family Support Administration

Requests in the FY 1992 Budget for Which Legislative
Authority has Expired or is Due to Expire on September 30, 1991

(Dollars in thousands)

APPROPRIATION / PROGRAM	EXPIRING AUTHORIZATION	AMOUNTS INCLUDED IN PRESIDENT'S BUDGET
75-1503-0-1-609 Refugee and Entrant Assistance	The Refugee Assistance Extension Act of 1986 (P.L. 99-605)	\$410,630,000

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Human Development Services

Requests in the FY 1992 Budget for Which Legislative
Authority has Expired or is Due to Expire on September 30, 1991

(Dollars in thousands)

APPROPRIATION/PROGRAM	EXPIRING AUTHORIZATION	AMOUNTS INCLUDED IN PRESIDENT'S BUDGET
Human Development Services		
-- Family Violence	-- Family Violence Prevention and Treatment Act	\$10,735
-- Child Abuse State Grants	-- Child Abuse Prevention and Treatment Act	19,518
-- Child Abuse Discretionary Activities	-- Child Abuse Prevention and Treatment Act	14,638
-- Child Abuse Challenge Grants	-- Child Abuse Prevention and Treatment Act	5,367
-- Temporary Child Care and Crisis Nurseries	-- Temporary Child Care for Children with Disabilities and Crisis Nurseries Act	11,055
-- Anti-Drug Programs for Runaway Youth	-- Anti-Drug Abuse Act	14,786
-- Anti-Drug Programs for Youth Gangs	-- Anti-Drug Abuse Act	14,786
-- Abandoned Infants	-- Abandoned Infants Assistance Act	12,557
-- Native American Programs	-- Native American Programs Act	33,376
-- Aging Programs	-- Older Americans Act	792,691
-- Adoption Opportunities	-- Adoption Opportunities Act	12,687

DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUMMARY

FY 1972-1992 TOTAL EMPLOYMENT

Authorized Positions, End-of-Year Employment, and Full-Time Equivalents (FTE)

	1972	1973	1974	1975	1976	1977	1978
Total authorized positions	97,770	110,420	122,336	126,349	130,934	135,881	138,148
Total, end-of-year employment	97,517	107,105	116,950	120,849	128,993	131,544	134,219
Total, FTE employment *	100,590	125,630	135,231	140,588	143,869	147,388	148,684

	1979	1980	1981	1982	1983	1984	1985
Total authorized positions	147,515	144,663	145,909	136,236	135,292	135,667	129,335
Total, end-of-year employment	138,647	136,432	139,865	132,851	134,085	131,715	125,592
Total, FTE employment *	158,250	156,544	148,038	142,082	141,456	136,761	132,096

	1986	1987	1988	1989	1990	1991	1992
Total authorized positions	125,909	120,823	119,613	118,060	118,343	120,838	123,192
On duty 12/31/90						110,974	
Anticipated on duty September 30						115,587	117,577
Total, end-of-year employment	120,644	116,360	116,378	115,714	117,699	115,603	117,608
Total, FTE employment *	127,183	121,798	119,041	117,942	118,057	121,792	124,723

* Work years shown prior to FY 1981.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUMMARY

New Programs in 1992 Budget
(Dollars in thousands)

APPROPRIATION / PROGRAM	1992 BUDGET REQUEST
<u>PUBLIC HEALTH SERVICE</u>	
Centers for Disease Control:	
-- Preventive Health and Health Services Block Grants Assessment Initiative	\$4,047
-- Immunization: Vaccine Incentive	20,000
-- Immunization: Vaccine Support	6,300
-- Program Management, Audited Financial Statements	235
Alcohol, Drug Abuse and Mental Health Administration:	
-- Consolidated Projects (Homeless)	20,000
-- Capacity Expansion Program	99,000
Subtotal, PHS (Labor/HHS)	149,582
Indian Health Service:	
-- Alcohol and Substance Abuse	83,510
Total, PHS	233,092
<u>HEALTH CARE FINANCING ADMINISTRATION</u>	
-- Survey and Certification	880,602
<u>FAMILY SUPPORT ADMINISTRATION</u>	
Family Support Payments to States	
-- At Risk Child Care	300,000
Payments to States for Day Care Assistance	
-- Child Care and Devel. Block Grant	731,925

DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUMMARY

New Programs in 1992 Budget
(Dollars in thousands)

APPROPRIATION / PROGRAM	1992 BUDGET REQUEST
<u>OFFICE OF THE SECRETARY</u>	
-- Clearinghouse on Third Party Liability	5,000
SUBTOTAL, HHS (Labor/HHS)	\$2,067,109
TOTAL, HHS	\$2,150,619

DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUMMARY

FY 1990-1992 UNOBLIGATED CARRYOVER BALANCES

and

FY 1990 LAPSED FUNDS

(Dollars in thousands)

APPROPRIATION	UNOBLIGATED BALANCES			LAPSED FUNDS FY 1990
	FY 1990	FY 1991	FY 1992	
<u>PUBLIC HEALTH SERVICE</u>				
Health Resources and Services Administration:				
-- Health Resources and Services	\$12,437	\$1,358	--	
-- Consolidated Working Fund	12,988	12,988	12,988	\$90,564
-- Medical Facilities Guarantee and Loan Fund	37,929	35,267	31,687	
-- Health Professions Graduate Student Loan	36,957	17,662	--	
-- Vaccine Injury Compensation Trust Fund	152,259	--	--	
-- Health Education Assistance Loans Authority	199,688	199,688	199,688	
Centers for Disease Control	4,537	8,508	--	85

DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUMMARY

FY 1990-1992 UNOBLIGATED CARRYOVER BALANCES
and

FY 1990 LAPSED FUNDS

(Dollars in thousands)

APPROPRIATION	UNOBLIGATED BALANCES		LAPSED FUNDS
	FY 1990	FY 1991	FY 1992
National Institutes of Health			
Alcohol, Drug Abuse, and Mental Health Administration:			
-- Alcohol, Drug Abuse, and Mental Health			
-- Construction and Renovation for St. Elizabeths Hospital			
-- Federal Subsidy for St. Elizabeths Hospital			
Agency for Health Care Policy and Research *			
* Includes \$423,000 unavailable pursuant to P.L. 101-239, Section 401C.			
	\$57,436	--	--
			\$1,121
	721	--	--
	594	--	--
	1,381	--	--
	464	--	--
			38,694
			41

DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUMMARY

FY 1990-1992 UNOBLIGATED CARRYOVER BALANCES
and
FY 1990 LAPSED FUNDS
(Dollars in thousands)

APPROPRIATION	UNOBLIGATED BALANCES			LAPSED FUNDS	
	FY 1990	FY 1991	FY 1992	FY 1990	
Office of the Assistant Secretary for Health:					
-- Public Health Service Mgt.	\$766	--	--	\$1,136	
-- Scientific Activities Overseas	50	--	--	5,667	
-- Service and Supply Fund	--	--	--	5,564	
Subtotal, PHS (Labor/HHS)	518,207	275,471	244,363	142,872	
Food and Drug Administration	37,078	521	521	64	
Indian Health Service	99,207	14,000	14,000	9,361	
Total, PHS	\$654,492	\$289,992	\$258,884	\$152,297	
<u>HEALTH CARE FINANCING ADMINISTRATION</u>					
Payments to Health Care Trust Funds Program Management	--	--	--	2,715,489	
	--	27,414	--	5,691	

DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUMMARY

FY 1990-1992 UNOBLIGATED CARRYOVER BALANCES

and

FY 1990 LAPSED FUNDS

(Dollars in thousands)

APPROPRIATION	UNOBLIGATED BALANCES			LAPSED FUNDS
	FY 1990	FY 1991	FY 1992	
<u>SOCIAL SECURITY ADMINISTRATION</u>				
Limitation on Admin. Expenses	\$10,271	\$145,087	\$22,977	\$65,939
Payments to Trust Funds	--	--	--	141,129
Special Benefits for Disabled Coal Miners	3,489	--	--	--
Supplemental Security Income	77,387	--	--	--
Total, SSA	91,147	145,087	22,977	207,068
<u>FAMILY SUPPORT ADMINISTRATION</u>				
Program Administration	931	--	--	1,697
Family Support Payments	43,148	10,000	10,000	--
Payments to States for AFDC Work Programs	--	--	--	71,314
Refugee and Entrant Assistance	3,528	3,528	3,528	100
Community Services Programs	--	--	--	340

DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUMMARY

FY 1990-1992 UNOBLIGATED CARRYOVER BALANCES

and

FY 1990 LAPSED FUNDS

(Dollars in thousands)

APPROPRIATION	UNOBLIGATED BALANCES			LAPSED FUNDS FY 1990
	FY 1990	FY 1991	FY 1992	
Low Income Home Energy Assistance Interim Assistance to States for Legalization	--	--	--	\$1
	--	--	--	137
Total, FSA	47,607	13,528	13,528	73,589
OFFICE OF HUMAN DEVELOPMENT SERVICES	104,990	1,276	4,576	879
OFFICE OF THE SECRETARY	651	--	--	2,086
OFFICE OF CONSUMER AFFAIRS	--	--	--	10
Subtotal, HHS (Labor/HHS)	\$762,602	\$462,776	\$285,444	\$3,147,674
TOTAL, HHS	\$898,887	\$477,297	\$299,965	\$3,157,109

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DEPARTMENT OF HEALTH AND HUMAN SERVICES
PUBLIC HEALTH SERVICE
ASSISTANT SECRETARY FOR HEALTH

1992 Legislative Programs
(Dollars in thousands)

APPROPRIATION/PROGRAM	BUDGET AUTHORITY	OUTLAYS
Office of the Assistant Secretary for Health:		
Adolescent Family Life	\$12,000	\$2,313
Disease Prevention & Health Promotion	4,577	4,512

T-6

DEPARTMENT OF HEALTH AND HUMAN SERVICES

HEALTH CARE FINANCING ADMINISTRATION

1992 Legislative Programs
(Dollars in thousands)

APPROPRIATION / PROGRAM	BUDGET AUTHORITY	OUTLAYS
<u>Grants to States for Medicaid</u>		
Proposed for Later Transmittal:		
1. Medically Needy Pregnant Women and Children	\$5,000	\$5,000
2. Medical Child Support Enforcement	(\$5,000)	(\$5,000)
3. Impact of Medicare Proposals	\$25,000	\$25,000
4. Transfer of Medicaid Survey and Certification to the Survey and Certification Revolving Fund	(\$91,500)	(\$91,500)

DEPARTMENT OF HEALTH AND HUMAN SERVICES

HEALTH CARE FINANCING ADMINISTRATION

1992 Legislative Programs
(Dollars in thousands)

APPROPRIATION / PROGRAM	BUDGET AUTHORITY	OUTLAYS
FEDERAL HOSPITAL INSURANCE (HI)		
Proposed for Later Transmittal:		
1. FICA: All State and Local Empl	\$1,234,000	
2. General Fund Transfer 1/	(\$20,402)	
3. Interest 1/	\$77,000	
4. Premiums Collected 1/	(\$17,000)	
MEDICARE PART A OUTLAYS		
Hospital Proposals		
5. Phase Down IME Adjustment		(\$1,045,000)
6. Limit GME Amts/Favor Primary		(\$140,000)
7. Offset Dup. Pymts. by Update		(\$10,000)
8. Hospital Update to Jan. 1st		(\$670,000)
Other Benefit Proposals		
9. Elim. ROE for Proprietary SNFs		(\$50,000)
10. Home Hlth Limits by Discipline		(\$90,000)
HI Share of HI/SMI Proposals		
11. Unif Disab/ESRD MSP Threshold		(\$55,000)
12. Medicare Coordinated Care		\$25,000
13. User Fee for Survey and Cert		
User Fee from State Cert		(\$138,391)
Adjustment for Benefit Offset		\$6,920

DEPARTMENT OF HEALTH AND HUMAN SERVICES

HEALTH CARE FINANCING ADMINISTRATION

1992 Legislative Programs
(Dollars in thousands)

APPROPRIATION / PROGRAM	BUDGET AUTHORITY	OUTLAYS
<u>SUPPLEMENTARY MEDICAL INSURANCE</u>		
Proposed for Later Transmittal:		
14. Federal Contribution 1/	(\$960,000)	
15. Interest 1/	\$12,000	
16. Increased Premiums for HI Income	\$41,000	
<u>MEDICARE PART B OUTLAYS</u>		
Physician Proposals		
17. Single Fee for Anesthesia Svc		(\$80,000)
18. One Fee for Surg, Asst at Surg		(\$50,000)
19. Correct Error in FY91 MVPS		\$0
20. Revise Medicare Economic Index		(\$30,000)
21. Elim Dup Fee, Specimen Handle		(\$10,000)
22. Efficient Rate for Rad./Diag.		\$0
Other Benefit Proposals		
23. Payments Unif Across Settings		(\$50,000)
24. 2% Update in 92/93, Below Cap		(\$20,000)
25. Reapply 20% Coinsurance		(\$450,000)
26. Refine DME Payment Methods		(\$35,000)
27. Enteral/Parenteral Fee Sched		(\$10,000)
28. Rebase Phys./Resp. Ther Pymt		(\$10,000)
29. Unif. Pymt. Policy, Cov Drugs		(\$10,000)
30. Extend DRG Pymt Window/Bundle		(\$30,000)
SMI Share of HI/SMI Proposals		
31. Unif Disab/ESRD MSP Threshold		(\$25,000)
32. Medicare Coordinated Care		\$15,000
User Fee for Survey and Cert		
33. User Fee from State Cert		(\$21,223)
34. Adjustment for Benefit Offset		\$1,060

1/ Not a separate proposal, but rather an income effect
of other income and outlay proposals.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

HEALTH CARE FINANCING ADMINISTRATION

1992 Legislative Programs
(Dollars in thousands)

APPROPRIATION / PROGRAM	BUDGET AUTHORITY	OUTLAYS
<u>Survey and Certification Revolving Fund</u>		
<u>Proposed for Later Transmittal:</u>		
Consolidation of Health Facility Inspection Programs From the Medicare Survey Activities, Medicaid Survey Activities, and a New Program of Clinical Laboratory Inspections Under the Clinical Laboratory Improvement Amendments of 1988.	N/A	N/A
<u>Program Management</u>		
Financing of the Medicare Survey and Certification Activity Under the Survey and Certification and Certification Revolving Fund	-160,000	-160,000
Financing of Survey and Administrative Costs Under the Survey and Certification Revolving Fund	-43,236	-43,236

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Social Security Administration1992 Legislative Programs
(Dollars in thousands)

APPROPRIATION / PROGRAM	BUDGET AUTHORITY	OUTLAYS
<u>Supplemental Security Income</u>		
Charge a fee from States which have Federally-administered State supplements (phase-in to occur over a 3-year period)	-\$60,000	-\$60,000
Permit recovery of SSI overpayments from OASDI benefits	-36,000	-36,000
Total, legislative proposals	-\$96,000	-\$96,000

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Family Support Administration

1992 Legislative Programs
(Dollars in thousands)

APPROPRIATION / PROGRAM	BUDGET AUTHORITY	OUTLAYS
75-1501-0-1-609 Family Support Payments to States:		
CSE Program Effectiveness	(\$54,000)	(\$54,000)
CSE Application/User Fee	(\$66,000)	(\$66,000)
Total	(\$120,000)	(\$120,000)

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Human Development Services

1992 Legislative Programs
(Dollars in thousands)

Appropriation/Program	Budget Authority	Outlays
<u>Human Development Services</u> <u>Extension Legislation</u>		
Family Violence Prevention	\$10,735,000	\$10,634,000
Child Abuse Prevention and Treatment	52,510,000	51,509,000
Temporary Child Care and Crisis Nurseries	11,055,000	10,915,000
Anti-Drug Abuse Act	29,572,000	29,576,000
Abandoned Infants	12,557,000	12,255,000
Older Americans Act	792,691,000	791,770,000
Native American Programs Act	33,376,000	33,306,000
<u>New Legislation Proposal</u>		
Child Welfare Services	<u>90,000,000</u>	<u>72,000,000</u>
Total, Human Development Services	\$1,032,946,000	\$1,031,935,000
<u>Payments to States for Foster Care and Adoption Assistance</u>		
Current Law	2,614,005,000	2,519,902
Savings associated with legislative proposal	-246,631,000	-209,636
Total, Payments to States for Foster Care and Adoption Assistance	\$2,367,374,000	\$2,130,266,000

DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUMMARY

Total Budget Authority by Fund

Fiscal Years 1972 through 1992
(Dollars in thousands)

Fiscal Year	General Funds	Trust Funds	Total
1972	15,264,299	43,207,460	58,471,759
1973	16,672,822	49,585,266	66,258,088
1974	17,207,480	57,703,306	74,910,786
1975	20,042,833	66,676,153	86,718,986
1976	23,682,544	70,682,325	94,364,869
1977	24,673,677	81,169,295	105,842,972
1978	43,575,360	89,594,736	133,170,096
1979	46,766,315	102,088,941	148,855,256
1980	55,846,605	117,439,214	173,285,819
1981	62,263,073	134,565,029	196,828,102
1982	65,045,753	148,027,089	213,072,842
1983	70,529,310	184,510,643	255,039,953
1984	76,818,931	180,582,158	257,401,089
1985	81,367,272	198,160,418	279,527,690
1986	84,745,149	205,773,237	290,518,386
1987	91,308,604	227,639,963	318,948,567
1988	102,893,171	259,056,279	361,949,450
1989	114,908,558	286,071,956	400,980,514
1990	126,214,366	307,921,178	434,135,544
1991	147,996,108	329,805,404	477,801,512
1992	160,808,344	351,064,968	511,873,312

DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUMMARY

Total Expenditures

Fiscal Years 1972 through 1992
(Dollars in thousands)

Fiscal Year	General Funds	Trust Funds	Total
1972	13,929,361	40,164,104	54,093,465
1973	13,519,466	49,098,471	62,617,937
1974	16,017,830	55,876,825	71,894,655
1975	20,390,217	64,668,094	85,058,311
1976	23,239,009	73,916,647	97,155,656
1977	24,075,665	85,081,662	109,157,327
1978	44,577,578	93,871,447	138,449,025
1979	47,372,654	104,085,672	151,458,326
1980	54,288,050	118,573,639	172,861,689
1981	60,689,217	135,316,823	196,006,040
1982	66,631,065	155,979,794	222,610,859
1983	74,029,202	170,849,266	244,878,468
1984	75,513,570	178,999,651	254,513,221
1985	81,714,630	189,444,841	271,159,471
1986	82,863,995	199,313,114	282,177,109
1987	89,363,115	208,141,522	297,504,637
1988	100,259,452	220,305,529	320,564,981
1989	112,846,711	233,677,675	346,524,386
1990	124,803,169	249,783,845	374,587,014
1991	147,711,774	269,443,651	417,155,425
1992	160,946,823	288,584,023	449,530,846

DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUMMARY

Travel by Appropriations, FY 1990-1992
(Dollars in thousands)

APPROPRIATION	FY 1990	FY 1991	FY 1992
<u>PUBLIC HEALTH SERVICE</u>			
Health Resources and Services Administration	\$4,310	\$4,172	\$4,202
Centers for Disease Control	11,562	13,287	14,129
National Institutes of Health	19,025	21,554	22,772
Alcohol, Drug Abuse, and Mental Health Administration	3,208	3,925	4,081
Agency for Health Care Policy and Research	294	338	405
Office of the Assistant Secretary for Health	1,382	1,307	1,335
Subtotal, PHS (Labor/HHS)	39,781	44,583	46,924
Food and Drug Administration	13,482	15,982	17,842
Indian Health Service	29,488	33,380	28,918
TOTAL, PHS	82,751	93,945	93,684
<u>HEALTH CARE FINANCING ADMINISTRATI</u>	4,838	4,971	5,183
<u>SOCIAL SECURITY ADMINISTRATION</u>	21,776	20,171	21,120
<u>FAMILY SUPPORT ADMINISTRATION</u>	1,854	1,593	1,753
<u>OFFICE OF HUMAN DEVELOPMENT SERVIC</u>	1,174	1,300	1,786
<u>OFFICE OF THE SECRETARY</u>	7,092	7,025	7,006
Subtotal, HHS (Labor/HHS)	76,515	79,643	83,772
<u>OFFICE OF CONSUMER AFFAIRS</u>	55	47	48
TOTAL, HHS	\$119,540	\$129,052	\$130,580

DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUMMARY

PROGRAM MANAGEMENT AND PROGRAM SUPPORT COSTS

FY 1989 through FY 1992
(Dollars in thousands)

	OBJECT CLASSIFICATION	1989 ACTUAL	1990 ACTUAL	1991 EST.	1992 EST.
	PERSONNEL COMPENSATION:				
11.1	Full-time permanent	\$1,383,462	\$979,456	\$1,079,708	\$1,137,266
11.3	Other than full-time permanent	163,361	130,940	145,114	154,013
11.5	Other personnel compensation	65,823	40,269	45,352	47,893
11.8	Special personnel services payments	29,913	38,049	41,460	44,482
11.9	Total, personnel compensation	1,642,559	1,188,714	1,311,634	1,383,654
12.1	Civilian personnel benefits	318,826	223,089	244,870	259,844
13.0	Benefits for former personnel	85,123	92,972	102,113	178,256
21.0	Travel and transportation of persons	88,240	51,727	55,924	58,135
22.0	Transportation of things	21,249	8,510	9,150	10,220
23.1	Rental payments to GSA	87,128	62,846	70,020	77,362
23.2	Rental payments to others	30,444	29,696	31,284	33,216
23.3	Communications, utilities, and miscellaneous charges	89,037	51,579	50,571	48,359
24.0	Printing and reproduction	41,886	30,906	35,333	36,800
25.0	Other services	6,624,497	9,217,765	7,354,959	7,204,935
26.0	Supplies and materials	313,476	235,699	300,713	313,093
31.0	Equipment	173,166	133,684	121,750	131,473
32.0	Land and structures	66,582	10,119	37,932	9,272
33.0	Investments and loans	18,393	691	4,550	26,393
42.0	Insurance claims and indemnities	330,106,661	360,928,095	383,971,367	415,654,973
43.0	Interest and dividends	1,094,351	1,100,325	420,076	30,657
92.0	Undistributed	3,216,100	3,206,634	3,823,403	3,643,398
93.0	Limitation on Expenses	3,765,920	3,798,339	4,013,878	4,482,000
	Total, HHS	\$347,783,638	\$380,371,390	\$401,959,527	\$433,582,040
	End-of-year employment	117,445	117,718	121,841	124,745

DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUMMARY

ENTITLEMENT VS. DISCRETIONARY
AND
REQUEST VS. APPROPRIATION

(Dollars in thousands)

	ENTITLEMENT	DISCRETIONARY	TOTAL
FY 1983			
Request	54,558,601	12,156,731	66,715,332
Appropriation	59,466,291	14,741,476	74,207,767
FY 1984			
Request	61,024,928	12,464,440	73,489,368
Appropriation	63,458,519	15,050,337	78,508,856
FY 1985			
Request	66,048,662	12,705,148	78,753,810
Appropriation	67,469,260	15,538,787	83,008,047
FY 1986			
Request	70,926,583	14,665,168	85,591,751
Appropriation	72,209,083	15,733,453	87,942,536
FY 1987			
Request	72,408,974	15,055,463	87,464,437
Appropriation	79,373,598	16,308,814	95,682,412
FY 1988			
Request	89,251,051	15,211,503	104,462,554
Appropriation	91,085,243	16,392,572	107,477,815
FY 1989			
Request	99,419,205	16,537,019	115,956,224
Appropriation	101,953,905	17,846,493	119,800,398
FY 1990			
Request	108,623,259	17,313,502	125,936,761
Appropriation	114,497,028	19,078,878	133,575,906
FY 1991			
Request	125,835,016	20,750,987	146,586,003
Appropriation	129,295,840	22,557,839	151,853,679
FY 1992			
Request	146,565,075	22,569,162	169,134,237
Appropriation	--	--	--

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